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ABSTRACT

This guide and workbook is a tool to be used to assist people with disabilities to play an active role in their job search. It provides ideas and examples to help individuals with disabilities and their job coaches through the process. Chapter titles for the workbook include: (1) "Power and Influence" (Valerie Brooke); (2) "Equality" (Paul Wehman); (3) "It's Up to Us: Practice and Attitudes Can Not Be Legislated" (Valerie Brooke); (4) "Maximizing Opportunities and Resources for Employment" (Teresa Grossi); (5) "Consumer Advocacy and Supported Employment" (Paul Wehman); (6) "Customer Initiated Supported Employment" (Michael Barcus and others); (7) "Training in Self-Advocacy and Future Planning" (Ed Turner and others); (8) "Peer Mentoring" (Ed Turner and others); and (9) "Personal Assistance Services" (Ed Turner and others). The information packet also includes a newsletter, "The Customer Is Right," that focuses on personal assistance services in the workplace. A 12-minute videotape recording, "Today's New Workforce: An Untapped Labor Pool," accompanies the guide and is suitable for staff training as well as marketing supported employment to individuals who are interested in facilitating employment for individuals with significant physical disabilities. The content focuses on job restructuring and assisted technology applications. (Contains 17 references.) (CR)

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Advocacy & Supported Employment for People with Disabilities

A Guide & Workbook for Individuals with Disabilities & Service Providers

Edited by: Michael Barcus
Teri Blankenship
Ed Turner
Paul Wehman
Greta Galloway

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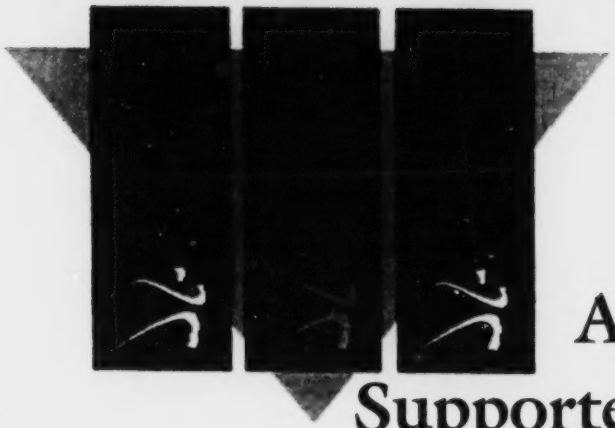

Advocacy & Supported Employment for People with Disabilities

A Guide & Workbook for Individuals with Disabilities & Service Providers

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> ***"Now is the time for a revolution that empowers all. Justice for All means Real Power for all, Real Choices for All, Real Access to the Dream for All."***

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Thanks must be extended to Valerie Brooke and Grant Revell for their assistance with the editorial process of this monograph. Finally, we are most appreciative of Jeanne Roberts for her layout and design expertise and her tolerance of our need to change just one more thing.

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Consumer Monograph *second edition*

Introduction

By: Paul Wehman

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This guide and workbook is a tool to be used to help people with disabilities play an active role in their job search. As we enter the new millennium, many changes will be happening in the workplace. These changes are necessary for companies to remain competitive in the global economy. It will be everyone's responsibility to develop competencies and skills to make themselves marketable and employable. Each person who wishes to work should be on an inward-looking journey to obtain employment or to remain competitive. It has been said that in the new millennium workplace, knowledge will be the new basis for success. But we believe that a positive attitude about working is just as valuable for success.

One exciting change in the new workplace will be companies recruiting a highly diverse workforce. The American workforce will have many different faces, which includes people with disabilities. Creative responses from businesses will develop such as voluntary reduced time, job sharing, flextime, telecommuting and flexiplace. Now is the time to advocate for yourself, and identify the necessary resources to become employed. This manual will give you some ideas, tips, and examples to help guide you through the process. We wish you good luck on your personal journey.

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Power and Influence

By: *Valerie Brooke*

The American culture is firmly rooted in a set of values that are strongly tied to power, control, and influence. Bookstores, newspapers, and magazine articles are filled with "feel good" stories about self-made millionaires, powerful CEO's of large corporations, and gifted athletes from humble backgrounds signing multi-year million dollar contracts. American's have a great fondness for these stories because they are about people who take control of their lives, accept the risks involved, make difficult decisions, set goals for themselves, and most importantly become successful in what they do.

Historically, individuals with disabilities have been denied access to the very events that would provide them with the opportunity to take risks, make decisions, and ultimately experience these highly prized American values of power, control, and influence. Further, due to a lack of economic resources or loss of specific skills, many people with disabilities are vulnerable and dependent on a human service system where they are stereotyped and stigmatized (Condeluci, 1991). Among medical and human service professionals, people with disabilities are viewed as recipients of services who have very little to contribute. Consequently, systems get created and service practices become institutionalized that lead to the disempowerment and dependency of people with disabilities.

For many individuals with disabilities, disempowerment and dependency seeds are planted while the person is very young. In many communities, young children who are attending special education classes ride a different school bus than the other children living in the same neighborhood who attend the same school. Typically, these "special" school buses pick-up students enrolled in special education classes in front of their homes instead of the regular bus stop where all the other children are waiting. As these young people grow into adolescents they begin to participate in programs designed only for children with disabilities, such as scouting programs, dances, and other leisure activities. These dependency seeds continue to grow as many of these young people reach adulthood and begin attending highly structured sheltered workshops where professionals are in charge and the opportunity for people with disabilities to make decisions, develop positive attitudes, and to achieve self-determination is greatly diminished.

Employment holds the key for undoing this dependency scenario for these individuals. For most adults, it is in the employment arena where informal networks of support are developed, goal setting is learned, decision making is fine tuned, and growth occurs. Yet for years, people with disabilities have been denied equal access to the many benefits and rewards of employment. Until very recently a rehabilitation professional had the authority to judge if a potential client had "rehabilitation potential" and thereby eligible for the rehabilitation

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services offered. Today under the 1998 amendments of the Rehabilitation Act this is no longer true. The Act clearly states that "disability is a natural part of the human experience and in no way diminishes the rights of individuals to live independently, enjoy self-determination, make choices for themselves, contribute to society, pursue meaningful careers and enjoy full inclusion and integration into the economic, political, societal, cultural and educational mainstream of society" (Section 101.2 (a) (3)). In addition, similar civil rights language has been added to other public laws such as the 1993 Developmental Disabilities Act. This public law adopted the same language as the 1992 Rehabilitation Act in the preamble of the Act.

Despite these very significant changes in the law, people with disabilities continue to face difficult situations when trying to access employment opportunities. In an effort to acquire some qualitative information from people with disabilities regarding their perceptions of the barriers and/or obstacles they face on a daily basis in obtaining competitive employment and/or the careers of their choice, the Virginia Commonwealth University, Rehabilitation Research and Training Center on Workplace Supports conducted a focus group of people with disabilities who describe themselves as being self-advocates. The twelve individuals who participated in this focus group ranked families, professional attitudes, and service systems to be the greatest barriers in achieving competitive employment (Brooke, Barcus & Inge, 1992). The table below describes these three issues as presented by focus group members.

Issue	Description of Issue	Personal Quote
Families	Many parents have trouble seeing their grown children as adults, making independent decisions. Yet, parents of children without disabilities have an opportunity to watch them successfully take risks over time. This has not been the experience of parents who have children with disabilities. Generally, we have grown up with segregated and highly supervised experiences, rarely making choices or taking risks.	*"My family has assumed the role of protector, and I'm not viewed as an independent individual."*
Professional Attitudes	Often, professional service providers think they know what is best for the people that they serve. This general air of condescension toward people with disabilities has many negative and far reaching implications which ultimately effect the achievement of personal goals. When professionals view persons with disabilities as "helpless," employers, family members, and the general public accept this same attitude. The end result is a pervasive continuation of negative attitudes and stereotypic images of persons with disabilities.	*"Professionals listen but they don't hear... They want to fit you into some stereotype that they learned in school."*

(continued)

Issue	Description of Issue	Personal Quote
Service Systems	Many service systems today are attempting to answer all the needs of persons with disabilities. This is an impossible situation and sets the service provider, as well as the customer up for failure. People with disabilities must begin to recognize the talent within themselves and begin to work the system rather than expecting the system to solve their problems. Part of working the system is obtaining information and ensuring that knowledge is built around how it operates. Getting this information can at times be very difficult. Questions need to be asked, information needs to be explained and services must be demanded if change is going to occur.	*"I waited for two years on a caseload only to find out that VR would not pay my school program to find me a job, because my parents make too much money. I think that I really fell through the cracks."*

As change begins to occur and power and influence are put into the hands of people with disabilities, many issues will arise. One of the major issues that will need addressing will be that people with disabilities must learn to accept power. The reasons why this does not occur automatically are a lack of experience with influence and power. While Kevin Pierce (1996) states that this reluctance among people with disabilites to accept power and influence is hardly irrational, especially among people who have long histories of dependency, it has failed to foster a cooperative spirit. This lack of a cooperative spirit could prove to be a major obstacle as services to people with disabilities move from a "systems approach" to a "customer-driven approach" of doing business. Customer directed services will require people with disabilities to gain experience, learn skills, and become confident if chronic unemployment among people with disabilities is going to end.

Summary

Individuals with disabilities have been denied services and experiences that would promote independence and power. The feeling of dependency and being "special or different" is learned at a very young age. In later life, people with disabilities are rarely given the opportunity to make decisions and to achieve self-sufficiency.

Employment would provide the life experiences that would help a person with disabilities become more independent, make choices, and to contribute to society.

Even with the changes in the law, people with disabilities continue to have trouble getting employment. They face obstacles such as the lack of a cooperative spirit between service providers and customers. People with disabilities must take on a pro-active attitude towards becoming employed and becoming empowered.

PERSONAL EXERCISE

EMPOWERING CUSTOMERS WITH DISABILITIES TO MAKE CAREER CHOICES

This chapter discussed many reasons why people with disabilities have not had experience making career related decisions. Certainly the process of making decisions is having basic information about jobs and the expectations explained in understandable terms. Below is an example of a customer-friendly career exploration questionnaire. Take the time to answer the following questions:

1. What types of activities and hobbies, do you enjoy doing?

2 Do you enjoy being or working in an "outside" or "inside" environment?
___ Outside ___ Inside

3. Do you want to work full-time or part-time?
___ Full-time ___ Part-time

4. How many hours a week would you like to work? No. of Hours: _____

5. What type of careers or jobs are you interested in?

6. How much money would you like to make in a week? Year?
Write dollar amount here: week_____ year_____

7. Do you like to travel? Do you like to travel out-of-town over-night?
___ Yes ___ No Day only travel
___ Yes ___ No Overnight travel

WRITING A CUSTOMER-DIRECTED INDIVIDUALIZED EMPLOYMENT PLAN:

Based upon your answers to the questions above, develop a individualized employment plan. Along with your career goal, identify any needed supports, services, training and/or assistive technology that might be necessary in order for you to reach your goal. Also decide on a reasonable timeline that you believe it will take to reach your goal.

Individualized Employment Plan

Career Goal: _____

_____

Date Plan Written: _____

Type of Service: _____

Date Needed: _____

Type of Support: _____

Date Needed: _____

Training: _____

Date Needed: _____

Assistive Technology: _____

Date Needed: _____

I want to be employed by the following date: _____

_____ _____
Customer's Signature Date

_____ _____
Counselor's Signature Date

Equality

By: Paul Wehman

• • • •

Society is accustomed to thinking that its' institutions and physical structures exist as if they represent the natural order of life. People tend to think that doorways and steps, buses and trains, and social practices have developed as they have because they reflect the needs of the general population. But a closer look reveals that there is nothing natural or preordained about buildings, communication services, or social practices. They have evolved as they have to meet the needs of particular groups, to the exclusion of others.

This is true everywhere. Steps are built at a certain height and doors at a certain width, not because some abstract principle establishes their size, but because they are designed to accommodate the needs of the average person. Telephones are designed for people who speak and hear. Social convention silently implies that places of social gatherings are meant for those who look "normal". Work schedules are designed for people who do not have any particular medical or child care needs. Trains and buses are designed for people who are ambulatory and, until the passage of the Americans with Disabilities Act (ADA), it was erroneously assumed by many that was the way they should be designed. Even when technology brings fundamental changes, such as improved communications through computer networks, most employers continue to believe that job applicants must be able to speak "normally" in order to perform a job successfully.

These assumptions have begun to be questioned. For example, some employers now organize work schedules to accommodate the needs of working parents with young children. In the area of transportation, we have learned that systems can and should be made physically accessible.

The ADA confronts society's assumptions with a powerful and even subversive message--social institutions do not have to practice exclusion. This message is not new; in fact, it has been inherent in disability litigation and legislation for the past 20 years, although it has rarely been so boldly articulated on the basis of equality. Yet advocates have commonly eschewed equality theories and instead have asserted some abstract 'rights', such as the right to accessible buildings, the right to decision-making authority, the right to special education services. These 'rights', while rooted in equality, tend to be asserted under a less problematic label, and therefore alleviate the tension between the two conflicting ideas of equality.

The ADA tackles the equality issue directly, constituting a non-discriminatory blueprint, as well as a blueprint for social change that will make equality truly a possibility for persons with disabilities. Its regulations assure that virtually all social institutions public and private, be required to make the proper changes so that a disability will not be an obstacle

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to equal opportunity. For example, if a train has a lift, it will not matter if a person is unable to climb the steps to reach the train. In the same respect, if an elevator has braille numbers, a blind person will not be impeded. As the ADA proclaims, a person's disability does not have to be a barrier to equal participation.

Unlike other laws, the ADA does not represent the traditional 'balancing' of one interest against another (although that certainly was part of the ADAs evolution). Rather, it is an exquisite compromise between the mandate that society adopt more inclusive policies and practices and the acceptance of the financial and administrative limits of reaching that goal. Its method is to build on the concept of reasonable accommodation, a familiar but minimally enforced concept that has its origins in the regulations of the Rehabilitation Act of 1973 (there is no reference to reasonable accommodation in Section 504 of the Rehabilitation Act itself, but it has appeared in all regulation interpreting that law). Reasonable accommodation powerfully bridges the gap between traditional and more recent concepts of equality by demanding that social institutions adjust to meet the needs of the person with a disability, not the other way around.

ADA and a Consumer Perspective

What do persons with physical disabilities think about the ADA? What has this law meant to them and what effect has it had on their lives? In order to have a full understanding of the impact of the law, we need to listen to persons with disabilities carefully.

For example listen to Jerry:

> *"I was called for jury duty. When I got there, I could see the jury box and the jury room were not accessible. I talked to the judge and he said he would write a few letters and he would call me back in one month. I got called back but it was a different judge and a different courtroom but the same problem – not accessible. He too said that he would write a few letters and he would call me back. Eventually, I did get to serve on the jury and it made me feel good to be able to do this, just like anyone else".*

Here is another voice, this one is from a young person with a severe disability:

> *"I have been disabled under two years and have been going to workshops to learn all I can about the ADA. These workshops are helping me to better understand my rights. After I learn, I tell my friends and family so they will know and be aware of what to watch for. I intend on being an advocate for the disabled because I'll be helping myself as well".*

Consider another woman with a physical disability who likes being able to go anywhere she wants to go just like a person without a disability. She says:

> *"If my son and I want to go somewhere and we need to buy tickets, we go where everyone else goes. I've had them try to tell me I need to go to a different place to buy tickets because 'you are disabled'. That's bull and a thing of the past, thanks to ADA. I also like*
>
> (continued)

the reasonable accommodations that have been made at my job. These accommodations made it possible for me to do my job well and my self-esteem is a lot higher. I really feel strongly that we need to make sure people do not weaken the ADA. Also, we need to be aware of what is going on around us. If you see a place that's not up to code, write them a letter telling them how they could meet the code. If that doesn't work, write a letter to file a complaint with D.O.J."

Here is what a person with a physical disability and four small children has to say.

"I have seen a lot more accessible parking. I can push my own chair, but with four small children I really need to be able to park as close to the front door whenever I go shopping as I can. Thanks to the ADA I can park near the front door, watch my children and still be able to do whatever shopping I need to do. Thanks once again to the ADA for restrooms I can get in and have room to keep my children with me".

Yet here is another story of a young man with a physical disability who was going to college. He said:

"Thanks to the ADA I got to go up on stage when the big day came for the handing out of the diploma. At first they told me I was not going to be able to get up on the stage to receive my diploma, I was going to have to roll in front of the stage. I said, 'No way, I will go on stage with the rest of my classmates'. They tried to tell me there was just no way this could be done, but I knew the law. It was my legal right to be on stage with my classmates. To make a long story short, "I did get a ramp so I could go up on the stage just like all the others. It really made my day. Hell, it made my whole year".

Consider a lady who has had a severe disability for some time. What impact has the ADA had on her? For example, she said:

"Just about everywhere you look you see curb cuts, this is great because just trying to cross the street was a life and death matter. Before the cuts, I had to find a way to get off the sidewalk and at the same time make sure there were no cars coming. Plus, I had to make sure that once I made it there was a way to get on the sidewalk on the other side. I didn't get all this gray hair just because of my age". She said she enjoys going out to eat and thanks to ADA, it's much easier because of so many accessible restrooms. "Before I would call to ask if they had an accessible restroom. Sometimes they said yes and later I'd find out they didn't. We still have a long way to go but the ADA is making the difference. I also see there are a lot more buildings that I can access. I really like having ramps I can get up and if the place has power doors it makes it even better".

These comments tell the story about what this law has done. But there is much more which remains to be done and other obstacles lay ahead, such as health care and benefits issues.

PERSONAL EXERCISE

"ADA & EQUALITY"

This chapter looked at the impact of ADA and the work that still needs to be accomplished in order for persons with disabilities to gain true equality. Testimonials from the consumer perspective are given to describe what ADA has meant to them and the impact it has made on their lives.

The following are key points to remember about the Americans with Disabilities Act (ADA) and employment.

1. It is unlawful to be denied a job due to a disability.

2. Qualified employees with disabilities have the right to be accommodated through the entire employment process.

3. Employers must accommodate qualified employees with disabilities unless it causes an undo hardship

   NOTE: It is important for customers to remember when employers claim undo hardship, the bigger their business, the harder this will be to prove.

4. Qualified employees with disabilities have the right to seek promotions, to use all common areas, and to enjoy benefits as employees without disabilities.

5. Qualified employees with disabilities have the right to pursue administrative and legal remedies when discriminated against.

Now answer the following "True" or "False" questions about what employers can ask.

a. ___ True ___ False The ADA allows employers to make inquiries as to the nature of disability prior to a job offer.

b. ___ True ___ False Employers may not ask about an applicant's ability to perform job-related functions or questions about the need for reasonable accommodations.

c. ___ True ___ False After a conditional job offer is made, an employer may require medical exams and make disability-related inquiries if he/she does so for all employees entering in that job category.

ANSWERS: a -- False b -- False c -- True

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It's Up To Us: Practice & Attitudes Can Not Be Legislated

By: *Valerie Brooke*

• • • •

Charlie's twenty year career will soon end when he retires from his job as a utility worker with University of Richmond. Long before the Rehabilitation Act openly embraced employment services for persons with truly significant disabilities, defined presumption of ability, called for choice, recognized the need for long term supports, and pushed for careers, Charlie was working hard to establish his career. When Charlie went to work in the late 1970s, he had a case file with evaluation report language that included such statements as : "Charlie is a nice fellow but realistically he has no potential for employment"; and "Charlie is hopelessly retarded". Twenty years later he is proof of the power of true choice, the benefits of accepting risks, and the advantage of community participation aided by ongoing supports.

During the mid 1970s, Charlie's days were spent sitting in a church basement stringing beads and completing other craft-like activities. The story of his move from that basement to a career at University of Richmond is significant and perhaps historic. First, Charlie was a man of small stature with very little muscle tone and while he had some receptive language, he had no expressive language. During Charlie's time in school and adult services, no one had given his parents any hope that he could ever achieve competitive employment. Therefore, Charlie had very little home-based experiences with work and no industrial-based work experiences. Second, the University of Richmond did not have any previous experience supervising employees with significant disabilities. Additionally, they did not have any community employers available to give testimonials of people with significant disabilities achieving employment success. At that time, most individuals with significant levels of cognitive, physical, and/or psychiatric disabilities were going into adult activity or sheltered workshops, not jobs in the competitive work force. In fact these segregated centers and workshops were so popular twenty years ago and alternative options so limited, individuals were put on waiting lists for years at a time in hopes that someday they would get accepted. Finally, the extreme disincentives to employment during this point in history required individuals with disabilities to risk complete loss of all government benefits if they decided to pursue competitive employment. Charlie over came impressive odds to enjoy the benefits of competitive employment.

The growth in the disability rights movement and the independent living philosophy and services are the hallmark of the last twenty years (NCD, 1996). Advances in policy, science, and technology are supporting independence as never before (Bristo, 1996). Lachat (1988) described this period to include consumer control, cross-disability emphasis, and community-based/ community-responsive approaches and trends. Societal attitudes and stereotypes regarding the ability of people with disabilities have changed dramatically and are giving way to a new level of

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inclusion within our society. Evidence of the crumbling of old restrictive paradigms are witnessed across the spectrum of community experiences to include such examples as: 1) public policies that identify people with disabilities as a class of people subject to pervasive discrimination; 2) education reform with federal Goals 2000 which assumes that all children are ready to learn; 3) technology advances and the endorsement of the "universal design" concept that benefits people with disabilities as well as other; and 4) community housing innovations that demonstrate creative financing and maximize choice and autonomy are visible lo‹ ally. Yet, nowhere is this inclusive attitude more evident then in the employment arena. This editorial will trace the patterns of progress in employment policy, services, and outcomes for people with disabilities that are framing this new open, more inclusive society.

Historical Overview of the Vocational Rehabilitation Act

Since 1918, the federal and state vocational rehabilitation programs have served as the government's key gateway to the employment of people with disabilities. Over the years the public law governing the state vocational rehabilitation agencies has been amended and extended to keep pace with societal trends. The following table presents an historical snap shot of the public laws associated with Vocational Rehabilitation Act, significant changes, and reflection of societal trends.

The middle of the 20th century has been referred to as the "Golden Era of Rehabilitation" due to significant increases in rehabilitation funding and the resulting expansion of services for persons with physical and mental disabilities. Yet, the guiding social trend and resulting practices were assembled around a medical model emphasizing clinic or center-based approach of "fixing or curing" people with disabilities with restorative and other types of services prior to employment. Therefore, while vocational rehabilitation was providing some services to people with mild levels of developmental disabilities, the majority of people with developmental disabilities were unemployed, living in institutions or with families, and generally dependent on a high degree of state care.

Table 1: Historical Overview of the Vocational Rehabilitation Act

Time Period Public Law & Policy	Societal Trends
Middle of the 20th Century -- Federal/state rehabilitation programs received large increases in funding. Participation limited to acquired disabilities with a clear demonstration of employment potential. **PL 113 of 1943; PL 82-565 of 1954; and PL 89-333 of 1965**	**Medical model** with veterans and those who acquire a disability representing the majority of persons being served. The majority of people with disabilities are unemployed, live with families or in institutions where they are cared for by the state.

(continued)

Time Period Public Law & Policy	Societal Trends
Early 1970's -- Increased awareness of employment services to all eligible persons regardless of their disability and its severity. **PL 93-112 of 1973**	**Deinstitutionalization movement** begins primarily for persons with psychiatric disabilities. Beginning of "equal opportunity: with IL Centers receiving funding, civil rights of people with disabilities advanced.
Later 1970's -- Provided a clear delineation of employment rights with affirmative action provisions and funding for IL services. **PL 95-602 of 1978**	**Readiness model** is a strong concept with people with disabilities earning their way to the next level of least restrictive alternative on the continuum. Services are developed around security, consistency, and safety.
1980's -- National examination of values and approach to rehabilitation. Expanded the Act to include a definition and funding for supported employment. **PL 99-506 of 1986**	**Functional supports** for all persons regardless of the level or type of disability is the new emphasis and becomes the model for rehabilitation. The old readiness model is an out of date concept.
Early 1990's -- Amendments are guided by a statement of presumption of employability for most individuals with disabilities, provides for choice of services and service providers, defines integration, and emphasizes careers, not just entry jobs. **PL 102-569 of 1992**	**Personal dignity and natural supports** represents the predominant thinking of this period with a clear rejection of professional dominance.
Late 1990's -- Streamlined administrative procedures and expanded assurances for informed choice with individuals developing their own Individualized Plan for Employment (IPE). **PL 105-220 of 1998**	People with disabilities are taking control of their careers/lives. Policy leaders recognize that systems change needs to occur in federal organizations to remove barriers to employment for people with disabilities.

The 1970s, with the Rehabilitation Act of 1973 adding for the first time an emphasis on severe disability, brought an increased awareness of employment services to all persons regardless of their disability or its severity. By the late 1970s there was a clear delineation of affirmative action provisions to protect people with disabilities and the Independent Living Centers (IL) movement began with funding in the Rehabilitation Act Amendments of 1978. The 1970s saw the endorsement of normalization principles and the beginning of the deinstitutionalization movement, although it was primarily limited to persons with psychiatric disabilities. These events led to the advancement of the readiness model emphasizing a service continuum. People with disabilities had to earn their way to the next level of least restrictive alternatives and thereby gradually move from a highly supervised or sheltered level to varying

degrees of independence. Little real movement actually took place because minimal emphasis was placed on giving people with disabilities life experiences with supports in less restricted, more integrated community settings. As a society, employment services and opportunities for persons with a severe disability continued to emphasize security, consistency, and safety.

The 1980s were marked by an intense examination of national values and alternative approaches to rehabilitation services. In 1985, the Rehabilitation Services Administration funded the first of the grants to states intended to systematically develop community integrated employment opportunities and resources for persons with the most severe disabilities. The Rehabilitation Act Amendments of 1986 defined and funded supported employment for persons with severe disabilities for the first time within the vocational rehabilitation program. Gradually, movement away from the continuum, readiness-oriented notion occurred because too many people were getting stuck at the activity-oriented sheltered level. Developing and designing functional supports, including use of assistive technology, became the new way of assisting people with disabilities achieve success in competitive employment.

The Rehabilitation Act Amendments of 1992 reflected the most significant change in history with a clear push for competitive employment for all persons, despite severity of disability. These 1992 Amendments reflect the guiding philosophy and crusade that was occurring in the rehabilitation and disability rights communities. A new principle of "presumption of employability" was introduced with a clear message that most persons can benefit from employment, if given necessary services and supports. Due to a societal push away from professional dominance, the regulations developed for the 1992 Amendments gave guidelines for employment in integrated work settings, provision for participant choice, and direction that services were no longer about just getting a job but instead about assisting people with a disabilities frame and realize careers.

Workforce Investment Act of 1998

On August 7, 1998, The Rehabilitation Act Amendments of 1998 were signed into law as a part of the Workforce Investment Act (WIA). The process leading to this legislation reflects the intensive efforts between our branches of government, as well as such constituencies as individuals with disabilities, advocacy organizations, and service providers (RSA, 1998). The new Amendments governing the state vocational rehabilitation programs place an increased emphasis on people with disabilities guiding and controlling their own career paths. These recent changes call for exemplary accomplishments among rehabilitation professionals, people with disabilities, advocates, employers, and the general public. No longer can the same, tired old arguments be used to explain why people with disabilities remain in sheltered settings and are not achieving true competitive employment success. Table 2 on the following page highlights the recent changes in the Rehabilitation Act Amendments of 1998.

These new Amendments go beyond previous attempts of opening doors and inviting people with disabilities to be partners, to an astonishing new approach of defining and informing how service users and providers will execute their new roles of collaboration. This is evidenced by the new definition of choice, the expansion of the choice provisions, the new Individualized

Plan for Employment (IPE), and the guidelines for review and reevaluation of individuals in extended employment. Further, by developing linkage between services and systems, people with disabilities will now be afforded the same training programs and services available to others within the government sector.

Table 2 -- 1998 Rehabilitation Act Amendments

MAJOR CHANGES	1998 AMENDMENTS
Choice	VR participants will have an opportunity to exercise choice throughout the entire rehabilitation process ensuring that the necessary supports are assembled to ensure choice.
Expanding Choice	VR participants are full partners in the identification and selection of employments goals, services, and service providers.
Individualized Plan for Employment (IPE)	VR participants are to develop, monitor, implement, and evaluate services.
Streamline Eligibility	VR participants who are beneficiaries of Supplemental Security Income (SSI) and Social Security Disability Insurance are guaranteed quick and easy access to services.
Extended Employment	VR participants in extended employment or receiving subminimum wage will receive an annual review to assess if the goal of competitive employment is commensurate with the individual strengths, resources, priorities, abilities, capabilities, interest and informed choice.
Quality Outcomes	VR participants employment outcomes should reflect the changes in society and include self employment, telecommuting and jobs with full participation and benefits.
Linking Services & Systems	VR participants will have access to the same employment training programs and opportunities that are available in other sectors of the government.

TICKET TO WORK AND WORK INCENTIVES IMPROVEMENT ACT OF 1999

At a time when our economy is at record levels, the unemployment rate among working age adults with disabilities remains at approximately 75%. The potential loss of medical benefits or lack of access to adequate health insurance has been perhaps the greatest obstacle preventing individuals from leaving Social Security beneficiary roles and entering the workforce. Often people with disabilities have been determined ineligible for Medicaid and Medicare if they work, thus putting thousands of individuals in the position of having to choose between health care coverage and work. Individuals should not have to choose between obtaining a job and maintaining their medical benefits.

Through the tireless efforts of the disability advocacy community, the President signed the Ticket to Work and Work Incentives Improvement Act of 1999 on December 17, 1999. This Federal law makes it possible for people with disabilities to join the workforce without fear of losing their Medicare or Medicaid coverage. This new law: increases beneficiary choice in obtaining habilitation and vocational services; removes barriers that require people with disabilities to choose between health care coverage and work; and assures that more Americans with disabilities have the opportunity to participate in the workforce and lessen their dependence on public benefits. The following table highlights some key features of this legislation.

Table 3 -- Ticket to Work and Work Incentives Improvement Act

Removes Limits on the Medicaid Buy-In	Lets States remove the income limit of 250 percent of poverty (approximately $21,000), allowing them to set higher income, unearned income, and resource limits. This change allows people to buy into Medicaid when their jobs pay more than low wages but may not have access to private health insurance.
Creates the Option to Retain Medicaid Coverage	Creates the option to allow people with disabilities to retain medicaid coverage even though their medical condition has improved as a result of medical coverage. This act also provides $150 million over 5 years in health care infrastructure grants to states to support people with disabilities who return to work.
Creates a New Medicaid Buy-In Demonstration	Provides $250 million to states for a demonstration to assess the effectiveness of providing Medicaid coverage to people whose condition has not yet deteriorated enough to prevent work but who need health care to prevent that level of deterioration. For example, a person with muscular dystrophy or diabetes may be able to function and continue to work with appropriate health care, but such health care may only be available once their conditions have become severe enough to qualify them for SSI or SSDI and Medicaid or Medicare. This demonstration would provide new information on the cost effectiveness of early health care intervention in keeping people with disabilities from becoming too disabled to work.

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Extends Medicare Coverage for People with Disabilities who Return to Work	Extends Medicare Part A premium coverage for people on Social Security disability insurance who return to work for another four and a half years. Although Medicare does not currently provide prescription drugs that are essential to people with disabilities, this assistance will be available nationwide, even in states that do not take the Medicaid options.
Creates a "Ticket to Work" Program	The Ticket to Work Program will enable SSI or SSDI beneficiaries to obtain vocational rehabilitation and employment services from their choice of participating public or private providers. If the beneficiary goes to work and achieves substantial earnings, providers will be paid a portion of the benefits saved.

The Ticket to Work and Work Incentives Improvement Act is a milestone on the road to employment for people with disabilities who want to work. However, it does not make a single change at the State level. It is up to each State to determine how the Ticket to Work and Work Incentives Improvement Act will be implemented. It is not a solution, nothing will happen unless advocates become involved with determining how it will be implemented within each state.

SUMMARY

The American culture is firmly rooted in a set of values that are strongly tied to power, control, and influence. Bookstores, newspapers, and magazine articles are filled with "feel good" stories about self-made millionaires, powerful CEO's, gifted athletics from humble beginnings signing multi-year million dollar contracts. American's have a great fondness for these stories because they are about people who take control of their lives, accept risks, make difficult decisions, set goals and most importantly, become successful. Charlie is one of these successful people. He, unlike many people with disabilities, was not denied access to the very events that would provide him with an opportunity to take a risk, make decisions, and ultimately achieve the highly prized American values of choice, power, and control through employment.

Today people with disabilities can no longer be denied access to rehabilitation services because they are judged as not having employment potential. In fact the 1992 Rehabilitation Act defined disability as a natural part of human experience that in no way diminishes the rights of individuals to live independently, enjoy self determination, make choices, contribute to society, pursue meaningful careers, and fully participate in society. In addition, similar civil rights language has been added to other public laws with respect to people with disabilities.

Yes, there are still many barriers to employment for people with disabilities. Yet, these barriers have been reduced significantly from the time that Charlie went to work twenty years ago. Do public laws need to be strengthened? Maybe stronger laws would be helpful however, attitudes and practices can not be legislated! For example, during the last several years a great deal of time has been devoted to defining the concept of choice for public policy to ensure that the practice within rehabilitation promoted people with disabilities guiding and directing their own careers. Currently, a new process has been implemented to define the concept of competitive

employment. While most employers could very quickly define this concept perhaps these are necessary evolutionary steps that the field of rehabilitation must progress though before old constructs and attitudes can give rise to a truly open and inclusive community.

The advances made in the field of employment for people with disabilities over the last 20 years are indeed remarkable. Charlie's career does serve as a shining example of the many changes now encompassed fully in public law and formal policy. He faced in 1978 what seemed like insurmountable odds in making the risky move from that church basement to seek his place in the labor market that was defined by his abilities and productivity, not disability and dependence. Charlie beat those odds, as have thousands of others, and as could tens of thousands more if the actual principles and content of the Rehabilitation Act Amendments of 1998 were mirrored in the local community practice and attitudes. Instead, approximately 2/3s of working age persons with a disability are unemployed (NOD, 1998) in an economy where employers' unmet demand for workers is ever increasing. Now is the time to embrace the language and the intent of the 1998 Rehabilitation Act Amendments by developing strategies that: train key personnel on diversity, ensure that employment agencies understand a business approach, disseminate best practices, establish or reinforce intern or mentoring programs, track the hiring and promotion of people with disabilities, introduce and/or promote flexible scheduling polices, and promote competitive benefit packages.

Within a very short time span, a steady and dynamic progression from separate and protective services for people with disabilities has moved to a new level of inclusion within our society. As the evolution continues and the transfer of power and influence actually occurs, the chronic unemployment and underemployment of people with disabilities will come to an end. It is actually the working together that will ultimately make the difference to people with disabilities, to business recruiters, to human resource managers, to rehabilitation professionals, and to our nation's economy.

PERSONAL EXERCISE

The new Rehabilitation Act Amendments governing the state vocational rehabilitation programs place an increased emphasis on people with disabilities guiding and controlling their career paths. Please answer the following questions.

Are you currently receiving vocational rehabilitation services? ____ Yes ____ No

Were you provided a description of the services available? ____ Yes ____ No

Were you encouraged to share your employment wants, likes, and dislikes? ____ Yes ____ No

Did you have the opportunity to select your employment goal? ____ Yes ____ No

Did you assist in the selection of services you need? ____ Yes ____ No

Were you provided a list of service providers? Did you select your service provider? ____ Yes ____ No

Did you participate in the development of your Individualized Plan for Employment? ____ Yes ____ No

Do you understand your rights under the Vocational Rehabilitation Act? ____ Yes ____ No

Based on answers to the above questions, identify topical areas in which you need training and information. Check all that apply.

____ Understanding my rights under the Vocational Rehabilitation Act.

____ Strategies and tips for working with vocational rehabilitation personnel.

____ How to make service and support decisions.

____ How to make my vocational goals clear to my rehabilitation counselor.

____ How to develop a plan for obtaining the vocational rehabilitation services that I need.

____ How to resolve issues with my rehabilitation counselor.

____ How to select a service provider.

____ How to evaluate the quality of the services I receive.

Maximizing Opportunities and Resources for Employment

By: Teresa Grossi

Maximizing Opportunities and Resources for Employment (Project MORE) is Ohio's collaborative effort of Systems Change in Supported Employment. Efforts to address Ohio's systems change areas included the Consumer and Family Empowerment Team (CFET). The CFET was a statewide team designed to give persons with disabilities and family members equal participation and decision-making with developing and implementing systems change that would increase supported employment options for individuals with the most severe disabilities. The main focus of the CFET was to increase involvement and participation of consumers and family members and to increase consumer choice and self-determination. Consumers and family members of supported employment demonstration sites and members of the statewide consumer and family empowerment team were invited to a two day retreat where they responded to the following questions:

1. What does your dream job look like?
2. What do we need in order to get our dream job?
3. Making the "Systems" work for us!
   a. What are the Ohio Rehabilitation Services Commission (ORSC), Mental Retardation and Developmental Disabilities (MRDD), Mental Health (MH), and Education doing well to assist you in working in the community?
   b. What would you like to see the four agencies doing differently?
4. What is your responsibility in reaching your dream job?

What Does Your Dream Job Look Like?

Each of us have different goals and dreams in life relating to where we want to live, work, and play. The types of "dream" jobs described by consumers varied. Some consumers were able to provide detailed descriptions of specific jobs whereas others described specific work environment or conditions. Although the jobs described represented individual consumers interests, preferences, and desires, there were common threads in each description. It was clear that all consumers desired meaningful and productive work, in an environment that they can contribute and feel a sense of self-worth. Interestingly, not a single consumer mentioned money as a factor in designing their dream job.

Examples of the types of dream jobs included: market analyst, office secretary, working with children, punch press operator, working with people with disabilities, licensed counselor, construction worker, mailer (labels/folding), working with computers, cleaning houses/offices, and working with people.

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What Do We Need to Get Our Dream Job?

There are many roads to take to obtain your dream job. For most people, to get their dream job involves the support and assistance of many people, such as family, friends, specific training programs, agencies, and colleges and universities. Over 75% of the consumers responded to this question with the need of a team, specifically a Project MORE team, where agencies work together collaboratively to assist with employment options. The team must not be territorial and put someone in a predetermined "box," but rather interdisciplinary; a team where people do not say "we can't do that" but "how can we make this happen." It is very important to have someone on your team who knows you well and can advocate with you. Consumers must take the time to get to know themselves, their interests and preferences. Agency personnel must be well trained and listen to what the consumer wants rather than putting him or her into a predetermined mold that does not fit his/her interests and desires.

Some of the "tools" that are essential to obtain our dream jobs include an encouraging team of people who can provide the services to help you realize your goals. This involves transportation, additional schooling, personal assistants, computer training, and a personal knowledge of your own community's available resources.

Making the "Systems" Work For Us!

a. What are each of the four agencies (ORSC, MR/DD, MH, and Education) doing well to assist you to work in the community?

A person-centered approach to planning highlights and builds upon the strengths and gifts of an individual. From a systems perspective, there are many strengths that each of the four agencies possess and offer quality services to people with disabilities. These strengths are highlighted below with need for a continuous process of evaluating quality through consumer satisfaction.

Ohio Rehabilitation Services Commission

- Provides a number of different types of services and supports,
- Links to other agencies,
- Support for equipment and services (job coaching),
- Connections to Project MORE,
- Adaptive equipment, and
- Excellent counselors.

Mental Retardation & Development Disabilities

- Family resource program,
- Case management resources,
- Transportation (in some areas),
- Fall-back programming, and
- Supported living.

Mental Health

- Decline in stigma of mental illness through increased public awareness,
- Ability to change case manager,
- Consumer Advisory Council,
- Job taxi, and
- Free services.

Education

- Increasing school integration,
- Functioning transition plans,
- Linkages to adult services,
- Work study and Option IV programs,
- Transition services,
- IDEA rights for students and families,
- Collaboration throughout summer, and
- Better integration at earlier age.

b. What would you like to see each of the four agencies that you are involved with do differently?

From a person-centered approach, the support and needs of the individual are addressed through a problem-solving approach. Via the systems perspective, needs were identified that the consumers and family members believed were barriers to positive quality employment outcomes for people with severe disabilities. Some of the areas identified dealt with the system as a whole, whereas others dealt with personnel issues such as the need for qualified competent service providers. These recommendations will be included in a 5-year plan to help improve the supported employment services in Ohio.

Ohio Rehabilitation Services Commission

- More consumer control on how the money is spent (choice of service providers) and in the decision-making process,
- Listen to the consumers desires and interest; not relying on evaluations,
- Deliver on the goal of serving those with severe disabilities,
- Clarify the definition of the most severely disabled,
- Connect long-term supports earlier,
- Counselor's goals for closure drives decision-making for persons to serve,
- Place people in jobs of choice and interest (not just any job),
- Only look at existing programs,
- Increase use of community-based rather than formal assessment,
- Ensure evaluations are valid (e.g., liberator is working),
- Make sure of consumer satisfaction with services,
- See person as a person, not a disability,
- Consistency of services from counselors,
- More frequent contacts to update on services or progress,
- Creative allocating of funds, and
- Better match of interests and abilities -- do not try to adjust the person into existing programs.

Mental Retardation & Development Disabilities

- Put more money into community service,
- Supports around the person,
- Promote independency,
- Close segregated facilities,
- More accessible and reliable transportation,
- More community access,
- Listen to consumer wants and needs,
- Less paternalism, and
- Commit money to community life.

Mental Health

- Increase access for those without speech.
- Find solutions, do not blame.
- Increase skills of counselors who work with people with limited communication skills
- Empower consumer to understand self.
- More well-trained case managers.
- Smaller caseloads.

Education

- More integration in high school.
- Improve transition plans (make sure they are working).
- Better linkages to adult services.
- Provide staff inservice and parent training on transition.
- Flexible meeting times.
- Raise student expectations.
- More social opportunities.
- Teach more self-advocacy.
- More parent workshops to understand transition process.
- Continue summer programs.
- Not fitting person into a narrow defined program.

What is my Responsibility in Obtaining my Dream Job!

Knowing your rights and having knowledge about choices are just the beginning to acquiring a dream job. Getting one requires speaking up for yourself. Responses to the question of what your responsibility is in obtaining your dream job highlighted self-advocacy as the major responsibility of each individual. The responsibilities identified are listed below:

- Be your own advocate
- Be persistent and assertive
- Believe in yourself
- Make a commitment and never give up
- Don't let others tell you something you don't want to do
- Pick your battles
- Thank providers for good work
- Network
- Take control
- Have faith/trust
- Make sure you are satisfied with services - Communicate
- Take risks
- Educate yourself
- Take the initiative yourself to make things happen
- Share success and failures with others
- Bring people to your meetings who really know and believe in you
- Don't leave job development to one person - apply with or by yourself
- Request frequent communication regarding progress. Ask what to expect!!

PERSONAL EXERCISE

This chapter shares the views of individuals with disabilities and family members. The consumers talk openly about the issues regarding supported employment in Ohio to assist the consumers and family members in becoming their own self-advocates and improving self-determination skills. The consumers comments were guided by questions about the consumers' dream jobs. Participants were asked how the state's agencies could better assist them to work in the community as well as, what the participants' own responsibilities were in obtaining their dream jobs. You can apply their suggestions and comments to your own challenges to finding your desired job.

The questions below pertain to obtaining employment which is best matched for you. Answering these questions should help give you a better idea of what job would please you most.

1. **What are some ways that you can advocate for yourself in your job search? (An example is to participate in contacting employers.)**

2. **List some jobs that you are interested in. Can you pick out similarities in these jobs (for example, working with people or working with computers)?**

3. **Knowing which elements you prefer in a job, why do you think you would be good at performing those tasks (for example, do you have experience working with people)?**

Consumer Advocacy and Supported Employment

By: *Paul Wehman*

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In recent years there has been a rekindling of interests in expanding services and improving accessibility for people with physical disabilities and sensory impairments. Consistent with the movement in society toward automation and application of technology, the Americans with Disabilities Act (ADA) and the accompanying regulations were signed by President Bush and published on July 26, 1991 in the Federal Register, which provided the impetus for people with all disabilities to participate in the labor force, as well as the community to a greater extent.

The resulting attention towards assisting people with physical disabilities, in addition to continued interest for those with mental disabilities, has increased the focus on individuals with disabilities speaking up for themselves. Specifically, there are hundreds of thousands of people with a variety of disabilities who are speaking for themselves. They are voicing their concerns and needs; and yes, even angers and frustrations at a society which has forgotten them. While it is always difficult to trace the beginning of new directions in service priorities, it would appear that a major impetus for greater consumerism, technology, and family involvement comes directly from legislation like the American With Disabilities Act. When new directions are carved out with impending legislation, the general reason is an existing vacuum in the law and accompanying practices.

For example, millions of people with disabilities cannot get into movie theaters, grocery stores, shopping malls, and cannot access restaurant facilities in public places. Thousands of highly capable individuals who could work are either passively or actively discriminated against by business and industry because of an unwillingness to make often very inexpensive accommodations. The thrust of consumerism on the part of many people with physical disabilities and sensory impairments is to function independently and not depend on a paternalistic professional service delivery system which has historically ignored them.

With the advent of consumer rights, greater emphasis on client involvement in planning and decision making, and the passage of the Americans with Disabilities Act, many professionals, consumers, and families are wondering what this means for supported employment. Are the Americans with Disabilities Act and supported employment compatible? Do consumer advocates and Centers for Independent Living have common issues with supported employment programs? In short, how does the welcomed trend toward consumer involvement relate to supported employment? We at Virginia Commonwealth University Rehabilitation Research and Training Center have asked ourselves these very questions and find the two directions highly consistent and parallel with the mutual goal of inclusiveness and integration into the community.

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SUPPORTED EMPLOYMENT: A LOOK AT IT'S ROOTS

It may be beneficial to go back into time and take a look at how supported employment began. That is, take a look at how and why supported employment emerged as an attractive alternative for people with disabilities. As we have said on numerous occasions, new concepts do not arise unless there is a need for them. Supported employment emerged because there were thousands upon thousands of people with severe mental disabilities who were viewed as being incapable of working by most service providers and, for that matter, advocates as well. Their options in life were to be in a day programs, adult activity centers, sheltered workshops, stay at home, or perhaps even live in institutions. In the mid to late 1970's, a number of professionals began to experiment with different ways of providing services. The reason for this experimentation was primarily to meet a need; the need was for people to obtain competitive employment, earn a decent wage, develop a real work history, and to realize community inclusiveness.

Supported employment was developed to give individuals with disabilities a choice in the labor force. This service model focuses on consumer interest and provides an opportunity for individuals to identify a job, specify the working conditions, determine the wage level, select the job location, and decide the hours that they will work. With 140,000 people currently working in supported employment (Wehman, Revell & Kregel, 1998), it is clear that more and more individuals with severe disabilities are asserting their rights and going to work for the first time.

Supported employment will not succeed without consumer involvement. Supported employment programs cannot be effective and will not flourish without consumer and family participation, support, involvement, and a willingness to take the necessary risks that are inherent, with any competitive employment. The early consumers that entered the work force in the late 1970's and early 1980's were pioneers. They were willing to take the risks of losing their safe spot in an adult day program and enter competitive employment. In most states there were limited support systems to help replace them if they failed.

We think that the parallels between this type of risk taking and pioneering spirit by people with severe mental disabilities dramatically parallels visionary thinking and activities on the part of people like Justin Dart in the formulation of the American's With Disabilities Act. The roots of supported employment are deeply entwined in consumer interests, choice, and inclusion. These roots are what has made supported employment one of the most popular and sustainable programs in the United States even in the face of one of the more severe recessions that this country has seen since World War II.

WHAT ARE THE PARALLELS BETWEEN CONSUMER ADVOCACY AND SUPPORTED EMPLOYMENT

We see numerous overlaps in philosophies and a significant number of parallels between the recent emphasis on consumerism and the supported employment programs

which have rapidly emerged across the country. What follows are a series of these parallels and consistencies. All people who are working in the field of disability, especially those who are service providers, should be aware of these philosophies and parallels to include the following:

1. The focal point of consumer advocacy and supported employment is persons with disabilities.
2. Real work is the outcome which consumer advocacy and supported employment programs both wish to see happen.
3. Consumers participating in consumer advocacy and/or supported employment programs have had their potential grossly underutilized.
4. Supported employment and consumer advocacy programs have proven themselves to be substantial.

1. The focal point of consumer advocacy and supported employment is persons with disabilities.

Traditionally programs that provide services to people with disabilities have delivered them in large groups and in an aggregate format, i.e., sheltered workshops and large institutional settings. Supported employment does just the opposite. Highly effective supported employment programs, for the most part, provide individualized services and support to the individual worker based on what he or she wants and needs. For example, if the consumer in question has a brain injury and does not want or need frequent visits to the work site from an employment specialist, then the employment specialist will do everything in their power to respect that wish. On the other hand, if a person with a long-term mental illness is extremely nervous and anxious about employment, as is a family member, then the employment specialist will make himself/herself available on a more frequent basis.

2. Real work is the outcome which consumer advocacy and supported employment programs both wish to see happen.

In so many programs that serve individuals with disabilities, the outcomes and goals are very unclear. The bureaucracy of service delivery seems to suffocate the intent of the program, and the individual is classically "lost in the shuffle." A major strength of the consumer advocacy movement and the supported employment movement is that the goals and outcomes are very clear in terms of what all wish to see happen--a competitive job with the opportunity to earn a decent wage and work in good conditions is paramount. This type of singular focus becomes very empowering to professionals, advocates, and consumers who work in this environment. All involved know what they are there for, and how their success or lack of progress is measured.

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3. ***Consumers participating in consumer advocacy and/or supported employment programs have had their potential grossly underutilized.***

Whether it is people with severe mental retardation, severe autism, and/or other severe cognitive disabilities in the 1980's or people with severe spinal cord injuries or severe cerebral palsy in the 1990's; many of these individuals have been "wasted" in terms of their human potential. These people have been considered by professionals as well as the business and industry community to have little to offer, to be too expensive to work with, and generally to be poor investments for vocational rehabilitation. What could be more devastating to one's self esteem than to be written-off in this fashion? Yet, in fact that is exactly what has happened, resulting in perhaps the most striking parallel between the two movements. The same motivations for those that wrote the Americans with Disabilities Act were shared by those that pushed and promoted supported employment opportunities for thousands of people with mental disabilities.

4. ***Supported employment and consumer advocacy programs have proven themselves to be sustainable.***

A fourth parallel which immediately comes to mind is the fact that weak programs, weak concepts, and "flash-in-the-pan" innovations will not last. Agency heads will not fund such programs and they will not generate the type of outcome data that warrants funding in tight times. Supported employment began approximately 18 years ago and has endured during two recessions; in 1981-82 and 1990-91. Supported employment has withstood the still all too frequent detractors who are only satisfied with the status quo of human service delivery programs. Consumer advocacy programs and other advocates of the Americans With Disabilities Act have fought for over five years, and in some cases even longer, to get the type of federal legislation in place which can begin to right the wrongs which have developed into our society's attitudes towards people with disabilities.

Consumer advocacy has staying power, because, like supported employment, it is the right thing to do. The best concepts are not only those that work, but those that make sense to people on a moral as well as common sense basis. After all, why wouldn't one seek input from the very people that are being served in disability programs? Why wouldn't those individuals help run those programs and take leadership roles in them? Why wouldn't those individuals with disabilities provide feedback about how to change those programs? It is common sense to do this; it is the right thing to do; and it is only a matter of time before this type of consumer advocacy and involvement spreads like wild fire.

CONSUMER ADVOCACY AND SUPPORTED EMPLOYMENT: WHAT ARE THE CHALLENGES?

There are a number of issues which must be resolved and taken into account as we consider the linkage of consumer advocacy and supported employment concepts. The first issue is that each of these major concepts have different constituencies of people with

disabilities. For example, the consumer advocacy movement in recent years is most closely identified as people with physical disabilities and other groups of people with disabilities that are able to articulate for themselves. They are able to express what their needs, wishes, and hopes are in terms of society being responsive to them.

On the other hand, supported employment has been and continues to be most closely aligned with people who have mental retardation and mental illness as their disability. These are two groups of people who are often unable to clearly articulate for themselves or receive the respect that is necessary to make their wishes and needs known. Subsequently, the idea of an employment specialist or a job coach arose to assist this group of individuals in gaining entry into the labor force. In fact, in the late 1970's when we began our work in supported employment, the term used to identify the supported employment service provider was "trainer-advocate." This term was used to recognize the dual role of the employment specialist on behalf of the person. Hence, the first issue that must be resolved in merging these concepts is for the two major groups of disabilities, physical and cognitive, to communicate more frequently and understand the differing points of view that each hold in wanting to make change in the system that provides services for people with disabilities.

A second very powerful issue involved is that those who are identified most closely with consumer advocacy generally have a number of goals that they wish to achieve in systems change. That is, transportation, personal care attendants, and improvements in quality of residential choices become paramount and overriding factors for thousands of people who are promoting greater consumer advocacy. Specifically, this means that as important as a positive vocational outcome is, there are other factors which weigh equally if not more important.

Those persons who are identified as primarily supporters of integrated and supported employment programs tend to have a somewhat more limited agenda. They are pushing work as the main change that they want to see occur in the system. In this sense, both groups have much to offer each other, since there are many people with physical disabilities who could greatly benefit from supported employment. In similar fashion, many supported employment participants and staff need to be more vocal in taking an activist role in other important life areas, i.e., transportation, independence in community living and so on.

A third issue which needs to be resolved between the two groups although very simple, is one that has a great deal of depth. Specifically, we are raising the point that consumer advocacy proponents do not always understand the philosophies or practices that are associated with supported employment. At the same time those individuals who are narrowly focused on supported employment as the only type of service issue do not recognize many of the consumer satisfaction, independence, and non-work disability incentive issues which occur on a daily basis for people who are associated with consumer advocacy programs. It is essential that both groups begin to attend each other's conferences. There needs to be greater professional communication and dialogue and a far greater integration and merging of mutual goals. The fire power of both groups working together as a cohesive lobbying force can have a tremendous impact on changing attitudes, values, and practices in society as well as influencing state and federal legislative action.

WHAT DOES THE FUTURE HOLD?

We see a very exciting vision of the future which merges the best of consumer advocacy and involvement with the most sophisticated job matching technologies and business and industry commitments. We see a period of time when assistive technology, electronics, robotics, and technological devices which have not even been invented yet will come into the work place to help empower the worker with a disability, his coworker or supervisor, and, as needed, employment specialist. In a sense, the employment specialist, other agents of supported employment programs, or Centers for Independent Living will provide the impetus for these technologies to be implemented.

The future of consumer advocacy programs, supported employment programs, Centers for Independent Living, technology transfer, and human behavioral interventions is in our hands. We have the greatest opportunities that we have ever had to integrate people with disabilities into the labor force. Jobs are available in all sectors, part-time and full-time for people with disabilities. The service delivery system and the community must work together to fill those positions.

PERSONAL EXERCISE

As you have read in this chapter, consumer advocacy and supported employment go hand in hand -- one does not work without the other or should we say work successfully without the other. To become a successful participant in supported employment you must advocate for yourself which affords you the opportunity to be in a competitive job environment, earn a competitive wage, work in good conditions, and decide the hours you will work. Supported employment is the way for individuals to become integrated into the community who otherwise would be lost in the system at sheltered workshops, adult activity centers, or day programs. As you can see, the key or starting point to achieve this employment goal is to become a well informed and skilled self-advocate while pursuing supported employment services.

Below are a few exercises to help you develop or expand your self-advocacy skills to enable you to become more involved in the planning and decision making for your future.

As stated previously, consumer advocacy is the key. Below are the "Six B's to Successful Self-Advocacy." After each point list several examples of being a successful self-advocate:

1. ***Be Self-Confident*: (example -- act like a customer shopping for a service)**

2. ***Be Informed*: (example -- be familiar with the service requested)**

3. ***Be Assertive*: (example -- be courteous but serious)**

4. ***Become a Proficient Self-Advocate*: (example -- know what you want)**

5. ***Be Persistent*: (example -- never take a "no" answer the first time)**

6. ***Become Familiar with how the Chain of Command Works*: (example -- if not satisfied, ask for the supervisor)**

Using your self-advocacy skills and your newly acquired supported employment knowledge, answer the following questions:

1. **List two obstacles/challenges you've encountered while trying to get services.**

2. **How do you think those obstacles/challenges could have been resolved or prevented all together?**

3. **If you are challenged with these obstacles/challenges again what will you do?**

4. **Explain why you feel supported employment is something that you could benefit from in the future.**

5. **List some aspects you have learned about yourself as a person and explain how these things about you could be beneficial when trying to find employment?**

After completing this exercise refer back to your answers when obtaining supported employment services or any time you need to advocate for yourself, be it finding employment that is best suited for you or in making everyday life decisions.

Customer Initiated Supported Employment

By: Michael Barcus, Valerie Brooke, Ed Turner, & Pam Targett

All too often the system makes decisions about our lives without involving us in the process. Fortunately this way of doing business is beginning to change. People with disabilities are speaking out, taking control of their lives, and seeking to direct the services they need. By law if you choose to participate in Supported Employment Services you should expect to receive competitive work in an integrated setting, with support and extended services. For instance listen to what one customer of supported employment services recently said:

◆ "Let me begin by telling you how I discovered supported employment. A friend of mine asked me to go with her to an appointment at a Supported Employment program, because she was nervous. I had heard about supported employment from another friend who was using it, but I really did not know much about it. Anyway, I agreed to accompany my friend. During the meeting, I thought this sounded like an interesting idea. So, soon afterwards I went to see my Rehabilitation Counselor, requested supported employment and that is when things began.

I knew which service provider I wanted; the same one my friend had chosen. During the first meeting we completed some paperwork. Then I was given the opportunity to either choose my employment specialist or have one assigned to me. I chose someone for myself, someone interesting and willing to assist me.

In order to look for jobs, the employment specialist needed to get to know what I wanted. She came to my house and asked me where I would like to work. I was interested in a job that would allow me to transport myself to work.

Next, we discussed how I wanted to find a job. I decided to contact businesses near my house. Also, my wife, myself, and my employment specialist brainstormed a list of businesses to contact. Eventually the employment specialist discovered an opportunity at a restaurant. The employer wanted someone to clean the dining area prior to opening. I had cleaned house and enjoyed this type of work, so I decided to check it out. During the interview, I told the employer I was a hard worker and dependable. I got the job.

The employment specialist went to work with me and provided recommendations on how to do the job. Today the employment specialist visits me on occasion to see how things are going. My success has been because I worked hard. I have come a long way, a year ago I had no job and look where I am now!"

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Is Supported Employment Right for Me?

This question may be somewhat difficult to answer if you have not had any type of work experience. One way to get a better feel for the supported employment service might be to talk with other individuals who have participated in this service or visit supported employment in action.

The following points may be useful when considering the type of work supports that may be appropriate for you.

- I have always wanted to work, but have never been able to obtain my goal.
- I have been told that I cannot work because of the severity of my disability.
- Employers say that I am not able to perform the job to their standards.

If you answer yes to any of the above, supported employment may be the work support you need.

How do I Choose a Service provider?

Once you decide to use supported employment services to assist you with obtaining employment, you will need to select a service provider. It is important to select a qualified supported employment specialist. If you are working with a rehabilitation counselor they should be able to provide a list of vendors and offer their personal recommendations. You should interview potential service providers to determine what services they have to offer you. The major work supports offered through customer-driven supported employment services are shown in the figure below.

Supported Employment Components

- Service Provider Selection
- Customer Profile
- Job/Career Development
- Employment Selection
- Job Site Training and Supports
- Ongoing Long-Term Support

Today, most communities have multiple supported employment service providers, and you as a customer may want to interview different programs to determine which organization receives your business. Your rehabilitation counselor should be able to provide you with a list of supported employment providers in your community. Make a list of interview questions.

Brooke, Wehman, Inge & Parent, (1995) offer a series of questions that as a customer you can use when preparing to interview supported employment service providers and to make a subsequent decision regarding employment supports.

Interview Questions

- Does your program have a written mission statement?
- What types of services does your agency offer?
- Do you have experience serving customers with different disabilities?
- How would you describe the role of the customer in supported employment?
- Have you excluded people with disabilities from your program (WHY)?
- Describe how you present your program to a perspective employer?
- May I see a copy of your marketing material?
- How many employment specialists does your agency employ?
- What is the average length of employment for your employment specialists?
- Do the majority of your customers have part-time or full-time employment?
- What is the average weekly earning of your customers?
- What types of jobs have you assisted customers in finding?
- Does your program assist customers with Social Security issues?
- Do customers choose their employment specialists?
- How do you fund extended services?
- What is the average length of employment for customers of your services? Do you have any reports?
- Do you have any references from customers, employers, and family members?
- How do you involve your customers?
- Does your program assist customers in accessing Social Security Work Incentives?
- Does your agency believe that all individuals can be competitively employed?
- What will you do for me?
- How do you assess customer satisfaction? Do you have any reports?

Invite a support person or note taker to accompany you to the interview. Ask about the provider's track record, if they have references, and talk to satisfied customers. After each interview organize your information and compare results to decide which provider will best meet your needs. Call the provider you selected to let them know why you selected their service and write a note to the ones you did not select letting them know why they lost your business.

What Next?

After selecting a service provider, it's time to interview staff and choose an employment specialist to work for you. A top-notch supported employment program will have no problems complying with your request. If you do not like the idea of selecting your employment specialist, ask the program manager, your rehabilitation counselor, or your self-advocacy mentor to assist you.

When interviewing an employment specialist ask questions that will assist you with determining who you want to work for you. Possible interview questions might include:

1. Tell me about yourself?
2. How long have you been employed?
3. What types of jobs have you assisted people in obtaining?
4. How will you involve me in the job search?
5. How will you involve me throughout the process?
6. Have you ever worked with a person who has a similar disability as mine?
7. What will you do for me?
8. Why should I choose you?

One of the key factors related to employment retention is the rapport that is established between the job coach and the customer. The employment specialist will play a key role in assisting you with your work supports.

GETTING A JOB!

You may enter into the efforts to locate a job with a clear understanding of your current interests and preferences already defined. If you are unclear about your goals, then the employment specialist should present a variety of options to assist with creating an employment profile. You will need to answer the following questions:

WHAT DO YOU LIKE TO DO?
- Interests
- Preferences
- Desires

WHAT SKILLS DO YOU HAVE?
- Talents
- Abilities
- Education

WHAT EXPERIENCES HAVE YOU HAD?
- Employment
- Volunteer/Training
- Personal Development

WHAT KINDS OF SUPPORTS DO YOU NEED?
- Personal
- Workplace
- Community

WHAT KIND OF SOCIAL ENVIRONMENT WOULD YOU LIKE?
- Co-workers
- Opportunities for Socialization
- Lunch/Breaks

WHAT TYPE OF JOB WOULD YOU LIKE?
- Type of work
- Location and Size of Company
- Advancement

WHAT WORK CONDITIONS WOULD YOU LIKE TO HAVE?
- Hours/Schedule
- Job Duties
- Work Environment
- Supervision

WHAT FINANCIAL/NONMONETARY BENEFITS DO YOU NEED OR WANT?
- Wages
- Health Insurance
- Vacation Holidays/Personal/Sick Time

JOB SEARCH

Once you have outlined what your needs are, now you must begin the search for your job. You and the employment specialist must determine your marketing approach and define what role each of you will have in exploring the job market. You need to develop an organized strategy for locating employment opportunities. You should play a key role in these efforts. Some examples of how you might get involved are listed below.

1. Develop a job plan of action which specifies both your involvement and the employment specialists involvement.
2. Participate in contacting employers.
3. Design and select marketing tools.
4. Participate in analysis of available jobs--read employment ads, use the Web to visit sites. (We've listed a few job web sites at the end of this chapter.)
5. Participate in interviews with employers.
6. Review pros and cons of each job.
7. Select the job that meets your demands.
8. Receive a written progress report from the employment specialist.

Analysis of the job market requires you and the employment specialist to become familiar with the local economy and availability of jobs within the community. A general analysis of the types of jobs currently available is a critical first step in the process of a job search. The intent is to identify all potential job types available and to determine what, if any, new forms of employment are emerging. Developing a comprehensive understanding of the local community's job market initially may require a considerable amount of effort and time but is necessary in order to develop jobs that are economically stable.

Once a clear picture of the local job market is acquired, it is time to screen the available market for potential jobs that may be appropriate for you. The purpose of this screening is to develop a working list of potential employment sites and contacts at these sites. The list should represent all jobs that are available in the community and not be limited to entry level positions. This is the tool from which the you will embark on the task of contacting individual employers.

After a working list of potential employment sites has been identified, you should begin to make specific employer contacts. Initially, preliminary information such as availability of job openings, general job duties, education and skill requirements, work hours, location, wages, and benefits should be collected . You will use this information to screen the job. If the position is determined to be potentially suitable, you will need to further pursue detailed information regarding the specific job requirements. This will entail an on-site observation to gather the information necessary performing the job.

EMPLOYMENT SELECTION

Employment selection begins as soon as you become involved in the supported employment process. You and the employment specialist should:

- identify job openings where your skills and knowledge meet the need(s) of the employer,
- schedule interview(s) with employer(s) for desired positions, and
- negotiate acceptable employment terms.

Preparation for the interview. You may want to participate in the interview by yourself or you may want the employment specialist to attend. Either way interviewing should be considered an opportunity for the employer to determine if they want to hire the interviewee, and opportunity for you to determine "Do I want to work here?".

To prepare for an interview you and the employment specialist will need to review and determine: (1) the purpose of the interview; (2) who will attend; (3) how you will get to and from the interview; (4) what the employer will want to know; (5) how to present your experience and qualifications; (6) what you will want to ask; and (7) how to act in a businesslike manner.

The Interview. The job interview should be viewed as a chance to gather information about the organization, the employer/supervisor, and the work environment. In some situations you and/or the employer may prefer that the interview be attended by the applicant only. In other situations, the applicant and/or the employer may want the employment specialist to participate.

Follow-up after the interview. You want to set yourself apart from other applicants. After the interview, you (with the support and/or assistance of the employment specialist) should write a brief note to the employer (the person you interviewed with). The note should include something positive about the way they treated you. Also, use the note as an opportunity to add anything you may have forgotten to mention at the interview.

Negotiate Acceptable Employment Terms

At the point in time when an employer makes you an offer of employment, you must make the decision of whether or not to accept the employment opportunity. The employment specialist may assist you with this process. However, it should be your decision, based on analysis of the facts, knowledge, and data that have been collected regarding the business and the specific job compared to your career/occupational goal. In essence, the task is to identify the consequences related to accepting or rejecting the position. You, with the support of the employment specialist, will need to determine the answers to several important questions:

- Do I want to work for this employer?
- Do I want to be employed in this work environment?
- Should I work full or part time?
- Will my wages & benefits be sufficient?
- How will my benefits be affected?
- Will I have transportation to and from my job?

Jobsite Support

Remember that the employment specialist has been hired to provide support services that should enhance your independence and success on the job. The employment specialist may take

on a role as facilitator of independent, self-directed learning or a job skills training specialist or anything in between in order to honor your preferences. You should be actively involved in the service implementation by:

- Communicating with the employment specialist on how you learn best.
- Recommending ways to enhance your job performance.
- Providing feedback on how you are doing on your job.
- Giving feedback on your overall satisfaction with their support.
- Selecting instructional support techniques you prefer.
- Identifying job accommodations you need.

ONGOING SUPPORTS

It is the employment specialist's responsibility to establish a regular ongoing schedule for review with you. This structured process focuses on gaining an accurate picture of the your situation and identifying activities necessary to maintain a high quality work experience. Over the years, some customers of supported employment services have voiced their concerns about the follow-along visits from the employment specialist. Typically, these issues centered around the intrusive practices used by some employment specialists to monitor consumer progress which were stigmatizing in the business setting. The intended goal of long term supports is to assist you, the customer, in the identification and provision of supports and extended services necessary to maintain and enhance your position as a valued member of the work force. You should:

- Determine when and where the employment specialist should meet with you.
- Determine how performance information will be collected.
- Determine how employer satisfaction will be assessed.
- Request any additional supports or services you deem necessary.
- Provide feedback to the employment specialists on your satisfaction with their services.

WHAT IF YOU FEEL THE EMPLOYMENT SPECIALIST IS NOT LISTENING

Any time during the process you feel that you are not being listened to by your employment specialist, try again and express that you feel you are not being heard. If that does not work, you should contact the employment specialist's supervisor. What if you still feel you are not being heard? Contact your rehabilitation counselor. Even if your case is closed, he or she should be able to help or give you a resource.

Staff advocacy offices usually have a client assistance program. Your state vocational rehabilitation program should have the telephone number if you need it. The advocacy office should be able to investigate and help solve your customer complaint issues.

PERSONAL EXERCISE

"SUPPORTED EMPLOYMENT FOR YOU"

Below are questions regarding supported employment and how to choose your service provider. Answering the questions and sharing them with your present service provider will help them learn more about your ideas and feelings regarding these issues and lend some insight for them into what your expectations of their service to you should be. If you are in the process of locating a service provider, refer back to these questions and answers to enable you to find a provider to best suit your needs.

Complete the questions as completely as possible adding any additional comments to assist your service provider in learning more about yourself and the type of employment you would be satisfied with:

WHAT DO YOU LIKE TO DO?

Interests: _____

Preferences: _____

Desires: _____

WHAT SKILLS DO YOU HAVE?

Talents: _____

Abilities: _____

Education: _____

WHAT EXPERIENCES HAVE YOU HAD?

Employment: _____

Volunteer/Training: _____

Personal Development: _____

WHAT KIND OF SOCIAL ENVIRONMENT WOULD YOU LIKE?

Coworkers: _____

Opportunities for Socialization: _____

Lunch/Breaks: _____

WHAT TYPE OF JOB WOULD YOU LIKE?

Type of Work: _____

Location: _____

Size of Company: _____

Advancement: _____

WHAT WORK CONDITIONS WOULD YOU LIKE TO HAVE?

Hours/Schedule: _____

Job Duties: _____

Work Environment: _____

Supervision: _____

WHAT FINANCIAL AND NONMONETARY BENEFITS DO YOU NEED OR WANT?

Wages: _____

Health Insurance: _____

Vacation Holidays/Personal/Sick Time: _____

Below is an additional activity to further your knowledge about supported employment and obtaining a service provider.

1. **Give some reasons why you think supported employment is right for you?**

2. **Make a list of questions you might like to ask a potential service provider during an interview.**

If you have access to the Internet, visit the following job bank web sites:

- CAREERS & the disABLED -- http://www.eop.com/may-cd.html
- The Disabled Businesspersons Association (DBA) -- http://www.web-link.com/dba/dba.htm
- EmploymentSpot -- http://www.employmentspot.com/
- JobAccess -- http://www.jobaccess.org/
- Midwest Institute for Telecommuting Education (MITE) -- http://www.mite.org/
- National Association of Temporary and Staffing Services (NATSS) -- http://www.natss.org
- Network for Entrepreneurs With Disabilities (NEWD) -- http://www.ability.nx.ca/entrepreneur/index.html
- Workforce Recruitment Program -- http://www50.pcepd.gov/pcepd/projects/workforc.htm
- The National Business and Disability Council (NBDC) -- http://www.business-disability.com/home/asp
- WorkSupport.com -- http://www.worksupport.com
- Able to Work (Microsoft & NBDC) -- http://www.abletowork.com
- WEMEDIA -- http://www.wemedia.com

Training in Self-Advocacy and Future Planning

By: Ed Turner, Chris Barrett, Paul Wehman, & Michael Barcus

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In the past, individuals being served in the vocational rehabilitation system have not been able to direct their own service plan or pursue their career interests. What enables some individuals with significant disabilities to overcome the challenges in becoming gainfully em-ployed while others with less severe disabilities sit at home or work in sheltered employment? It seems that people who achieve independent living and/or successful careers have been determined to control their own life and were skilled in self-advocacy (Turner, 1996).

Today, self-determination has been incorporated into disability related legislation. Specifically, the Rehabilitation Act Amendments of 1992 (PL 102-569) declared the right of individuals to enjoy self-determination. All programs and activities funded under the Act must promote the principle of self-determination. Self-determination has been described as the power to choose and pursue one's own interest and desire to direct one's own destiny (Knight and Davis, 1987).

The goal of self-advocacy, self-determination, and future planning would probably not have been included in consumer training as recently as 10 years ago. Only since the passage of the Americans with Disabilities Act in 1990 and literature published within the last 5 to 7 years has the consumer movement in disability been documented. Self-advocacy is grounded in the roots of freedom, choice, and self-determination, all of which are fundamental values that all U.S. citizens are entitled to enjoy.

Many individuals with disabilities, particularly severe disabilities, have been taken care of or made to be highly dependent on others. This has fostered a great deal of what psychologists call "learned helplessness." The experience of learned helplessness--not being able to be independent for oneself and one's needs--is widespread in the disability com-munity. The only way to begin to offset this debilitating way of life is for schools and other service providers to promote greater personal competence.

Increasing numbers of programs are teaching self-advocacy skills to people with disa-bilities to help them gain knowledge about their rights and the choices available. Unfortun-ately, knowing one's rights and choices available to them are still insufficient for many people, often an assertive personality is required to make one's interests and needs known.

The goal of self-advocacy is a very real one for people with disabilities as they (a) fight for the services to which they are entitled, (b) gain information and knowledge about the types of financial entitlements from the state and federal government they may be eligible to receive, and (c) become aware of what is going on in their community that could positively or negatively affect them. There are many ways to foster self-advocacy. For example, individuals can be taught when shopping how to ask for assistance or how to file a complaint with the manager if they are unhappy with the service they received.

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The concept of self-advocacy goes beyond knowing the disability laws, and instead questions the whole area of community participation and knowledge of civic relationships that can affect the person and his/her family. The main reason self-advocacy is an im-portant goal for people with disabilities is because of the limited financial resources available. Individuals who can take advantage of what services are available will be more likely to receive those services than the person who sits passively on a waiting list.

Training in self-advocacy should focus on the basic tenets of the Americans with Disabilities Act, which is a civil rights law for people with disabilities. Essentially, the ADA provides the statutory framework for equality in accessing telecommunication and transportation services and promises nondiscriminatory action as related to employment. No other country in the world has such a powerful law on behalf of citizens with disabilities, yet the ADA will be of limited value if the individuals it is targeted to help are unaware of how to take advantage of it.

The other major law which people with disabilities should be aware of is the Rehabilitation Act Amendments, specifically the vocational rehabilitation services in their community for which they can become eligible. Finally, information about Social Security and Medicare should be made available to everyone as they become older. The team should find a contact person at the Social Security office with whom the they can communicate and are comfortable with in order to understand how to access Social Security information. Most states or communities also have protection and advocacy services.

Self-advocacy training needs to be highly practical, directly tied to the local community services and to the needs of the particular person. For some people this may not be a necessary goal, but it would appear that most people could benefit as they likely will need to know how to best advocate for services or to obtain help within the community. Being trained in self-advocacy skills will be a way to help ensure personal success.

The need to empower individual consumers of rehabilitation services is critical. Virginia Commonwealth University's Rehabilitation Research and Training Center on Workplace Supports (VCU RRTC) initiated a Self-Advocacy Leadership Institute training program designed to foster self-determination among individuals with disabilities by providing information on federal laws, self-advocacy tips, decision making, and negotiating skills. Individuals with disabilities are the lead instructors for delivering these training events. The purpose of the Institute is to provide individuals with disabilities an opportunity to become aware of their rights to access employment, transportation, and other aspects of community living.

BASIC SELF-ADVOCACY LEADERSHIP TRAINING

Each Institute is designed to make participants aware of their rights and give strategies for making choices regarding employment options. The overriding theme is to assist participants in becoming aware of their right to manage their own career planning. The following table lists the guiding principles for the Self-Advocacy Leadership Institutes.

Key Principles of the Self-Advocacy Leadership Institute

- People with disabilities need to have self-advocacy skills to deal with service delivery systems (i.e., vocational rehabilitation, social security)
- Training areas provide information on federal laws, vocational rehabilitation services, Social Security Administration and work incentives, Medicaid, self-advocacy tips, decision making, and negotiating skills.
- Specific self-advocacy techniques are presented which enable customers to effectively work with the state vocational rehabilitation service delivery system.
- Training activities give customers opportunities to practice skills.
- A personal action plan is developed with each institute participant.
- The lead trainers are people with disabilities who serve as role models.
- The training site must be accessible and easy to reach with public transportation.
- Reasonable accommodations (interpreter and voice interpreters, personal assistance) are provided.
- Training materials are available in large print, braille, and audiotape.
- All materials that are used by presenters are included in participant notebooks.

Adapted from: Turner, 1995

Institute Curriculum

Institute trainers have developed an array of strategies for delivering the curriculum content to meet the diverse needs of participants. The self advocacy training focus includes techniques for improving self-esteem, disability specific information, interpersonal advocacy tips, rights and responsibilities, strategies for life assessment planning, and self-advocacy training (Peterson, 1995). The following guidelines are taught to participants to use when advocating for vocational services.

Advocating Guidelines

- ***Self-Confident***
  1. Act like a customer shopping for a service.
  2. Don't be intimidated.
  3. Keep eye contact at all times.

- ***Informed***
  1. Become familiar with the service requested.
  2. Learn the eligibility requirements.
  3. Ask follow-up questions to be sure you understand.

- ***Assertive***
  1. Set timelines when you expect to get answers about services.
  2. If timelines are not met, call again.
  3. Be courteous but serious.

(continued)

Advocating Guidelines (continued)

- ***Proficient Self-Advocate***
  1. Know what you want.
  2. Establish a reputation of one who usually gets what he/she goes after.
  3. Learn how to negotiate so you will always get your bottomline.

- ***Persistent***
  1. Keep calling or asking until your requests for services are answered.
  2. If "no" is the answer, ask why.
  3. Never take a "no" answer the first time.

- ***Familiar with Chain-of-Command***
  1. If not satisfied with the counselor's responses, ask for their supervisor.
  2. If not satisfied with supervisor's answer, ask to speak with their supervisor and keep moving up.

Adapted from: Turner, Wehman, Wallace, Webster, O'Bryan, O'Mara, & Parent, 1997

Training is provided on key federal laws such as the ADA, the Rehabilitation Act, and the Social Security provisions in order to enable participants to understand the legal basis for making choices about services. Basic definitions and examples of rehabilitation goals, services, providers, funding sources, supports and resources constitute the remainder of the Institute. Turner (1995) describes the Institutes' major training content areas.

Institute Content Areas

- ***Ice Breaker***

  This session is used to establish a comfortable atmosphere with the participants and gives them an opportunity to meet one another. A facilitator explains how using self-advocacy begins by speaking up for yourself with family members, friends, and co-workers.

- ***Levels of Self-Advocacy***
  1. Let your family members know about your needs and desires.
  2. Let your friends know your choices concerning recreation and social activities. Let a "special friend" know you would like to date them.
  3. Let your teachers or guidance counselors know what you would like to study.
  4. Let your vocational counselors know what types of services you need to find and keep employment and also know the types of jobs in which you are interested.
  5. If you work, let your employer know what accommodations are needed in order for you to do your job.

(continued)

Institute Content Areas (continued)

- ***The Americans with Disabilities Act (ADA)***

  Basic information is shared on the employment provision of the ADA and how these effect the employment process. Tips are provided on ways customers can use this law to their advantage in searching for employment. Exercises illustrating how the ADA can be used in everyday employment situations are developed

- ***The Rehabilitation Act & Supported Employment***

  Information on supported employment and how this service helps persons with severe disabilities find and maintain employment is provided. The 1998 Rehabilitation Act Amendments are explained along with how they give customers the right to choose supported employment services. The changes in services initiated by these Amendments, such as the presumption of eligibility for applicants with severe disabilities and the choice provisions are described. Tips are given on how customers can make the rehabilitation system work for them.

- ***Resolving Service Issues***

  A panel discusses options VR customers can use to exercise their rights to choose services. The VR agency's Internal Advocate's Program can assist customers to resolve service issues with their counselor. A member from the Department for the Rights of Virginians with Disabilities (DRVD) describes the Client Assistance program and how customers can access those services. Another member talks about how customers should use self-advocacy to make their vocational goals and service needs clearly known to counselors.

- ***Understanding Your Rights Under Social Security***

  A representative from the Social Security Administration (SSA) presents basic information on the various work incentives offered for recipients of SSI or SSDI. The group is given the opportunity to share their experiences with the Social Security system and ask specific questions.

- ***Making it Happen***

  A panel of self-advocates describes their own experiences using self-advocacy techniques and why they had to develop effective self-advocacy skills to overcome barriers to employment. Specific techniques include effective decision making, assertiveness, negotiation, importance of following through, and dealing with stonewalling situations.

- ***Getting into the Act***

  Facilitators present scenarios about people with disabilities having difficulty obtaining vocational and supported employment services. Participants have the opportunity to practice using self-advocacy skills to solve the service problems presented. After each role play, the group has an opportunity to suggest other ways for customers to get services and the facilitators offer suggestions on other ways the consumer could have solved the service problem.

(continued)

Institute Content Areas (continued)

- ***Local Resources***

  Participants are given the opportunity to get information about local providers of services. They also begin the development of a personal community resource notebook for their own particular city or county.

- ***Developing an Action Plan***

  Scenarios are presented which illustrate a problem a consumer is having obtaining VR services. Three participants discuss how to: (1) define the problem, (2) identify local resources, and (3) develop action steps for using identified resources to address the problem. Participants meet in small groups to develop personal action plans. Group facilitators work with participants in developing a personal action plan.

- ***Planning & Follow-Up***

  The purpose of this session is to brainstorm with participants ways to strengthen and improve future institutes. Staff seek specific recommendations as to what the content needs to be for follow-up institutes. The group explores ways in which supports can be provided when participants return home.

- ***Closing Session***

  Certificates of Completion are given to participants after an inspirational speech by a self-advocate.

Adapted from: Turner, 1995

Institute Participation

In 1994, to assist customers to meet this challenge, the Rehabilitation Research and Training Center (RRTC) on Workplace Supports hired an individual with a disability as a Training Associate. The mission of that individual was to established a Self-Advocacy Leadership Training Institute for customers of vocational rehabilitation services for two reasons. The first was, that the RRTC believes that having a knowledge of employment rights is essential to customers when making choices as to the services needed. Secondly, the Center believes customers who become proficient self-advocates are more successful in employment pursuits, as well as in other areas of their lives. Having a basic knowledge of their employment rights and having the tools to assert those rights will also better enable customers to work in partnership with their counselor and/or employment specialists.

To date, fourteen Self-Advocacy Leadership Institutes have been held in many different regions of Virginia. Some of the outcomes of these Institutes have been: 1) people with disabilities gaining employment for the first time, 2) improving their employment situations, 3) standing up for their rights for job accommodations, 4) improving their living situations, and 5) making their own choices in other areas of their lives.

The table on the following page summarizes participation during the past two and a half years of the Institute's history.

Institute Participation Summary
June, 1994 -- 1998

Institutions Held	17
Participants Trained	140
Action Plans Developed	69

Participant Outcomes

Participants are exposed to strategies for exercising choices in the rehabilitation system and techniques for providing direction to those providing service. They are introduced to skills for leading and facilitating teams, and given information on how to function proactively in the rehabilitation process while directing their own service plan. Individuals leave the In-stitute with a new level of self-awareness and skills on how to direct the rehabilitation process. The following table contains a sample list of participant outcomes.

Participant Outcomes

- 18 individuals obtained employment.
- 10 individuals were referred to and are receiving supported employment services.
- 10 individuals are serving as trainers or have been elected to leadership roles in consumer organizations.
- 4 individuals improved living situations.
- 2 individuals started GED programs.
- 2 individuals who were former CIL customers have become employees at that CIL.
- 1 individual has used ADA information to get a job accommodation.
- 1 individual is now directing a satellite CIL in Lynchburg.
- 1 individual with a substantial disability and a very limited employment history is now working in a restaurant.
- 1 individual with mental retardation and who is very passive became motivated and started a GED program. This individual used information learned from the ADA training to insist on a job accommodation to improve work performance.
- 1 individual with a visual impairment is now working for a federal agency. Taking this position meant having to relocate, obtain an apartment, and find transportation.

Achieving employment is a challenge to anybody; this is especially true for people with disabilities. For customers with significant disabilities, the unemployment rate remains at a staggering seventy percent. This still exists despite the passage of laws like the Americans with Disabilities Act (ADA) and the choice provisions that were included in the 1992 amendments to the Rehabilitation Act. Djuna T. Parmley is showing by her example, what can be accomplished by a person who has gained the knowledge and skills to make her dreams a reality.

Djuna T. Parmley, a person with a mobility impairment, attended the 1996 VATS-RRTC

pre-conference Self-Advocacy Leadership Training Institute with several of her co-workers. When Ms. Parmley attended the training she was working as a part-time administrative assistant for the Endependence Center of Northern Virginia (ECNV). During the training she asked many insightful questions about how to apply the knowledge and skills to improve her employment situation.

When the time came to develop an action plan about how to achieve the goal of full-time employment, Djuna had no doubt about what she wanted to do. Her goal was to become a full-time peer counselor at ECNV and to increase her income. A little over a year later, Djuna ran into the Institute's lead trainer at a national conference and proudly reported that she had become a full-time peer counselor at the CIL where she worked.

Although it is important to know Ms. Parmley increased her salary substantially, more importantly, she is doing exactly what she wants to do. She is now using her knowledge, skills, and experiences to support others in accomplishing their goals of becoming employed and being active participants in their community.

Most people would be well satisfied at the level of success that Djuna T. Parmley has enjoyed over the past couple years. This is not the case with Djuna, who has set her sights upon entering law school in the fall of 1999 and hopes to study corporate law and disability rights. Having established her reputation as a winner, few will doubt that becoming a lawyer will be accomplished by this determined young person.

This is a striking example of what can happen when a person implements a plan of action by using the knowledge and skills gained by attending the RRTC's Self-Advocacy Leadership Training Institutes.

PERSONAL EXERCISE

"HOW TO ADVOCATE FOR YOURSELF"

A part of advocating for yourself is the ability to make decisions. Below are five steps to decision making:

1. ***goal setting*** -- an end that one strives to attain.
2. ***collecting information*** -- gather facts concerning the situation.
3. ***process the information you collected*** -- review your information.
4. ***values*** -- what are your beliefs and standards.
5. ***consequences*** -- being willing to accept the results of your actions.

The following are important employment decisions you should ask yourself prior to locating employment:

- Should I work full-time or part-time?
- Will I need training for the job I want?
- Will my wages and benefits be as much as my Social Security Benefits?
- My disability is invisible. Should I disclose it or not?
- Will I like the work environment?
- I know more education will help me on the job, but do I have enough energy to work and attend class also?

Once you have given thought to these decision making steps and answered the above questions, complete the following Participant Action Form.

1. What are your current employment goals?

2. What are the greatest obstacles you face in your current employment or vocational situation?

3. Which of these obstacles can you do something about?

4. In terms of your goal what is the least you will settle for?

5. When do you expect to reach your goal?

Below is an Assertiveness Inventory which represents different areas of assertiveness. By rating your comfort level in each, you can increase your own awareness of areas that need work or improvement.

A score of 1 indicates that you are very uncomfortable with the behavior; a score of 3 indicates that you are completely comfortable.

Assertive Behaviors

___ Speaking up and asking questions at a meeting.
___ Commenting about being interrupted by a person directly to him at the time you are interrupted.
___ Stating your views to an authority figure (minister, doctor, boss).
___ Attempting to offer solutions and elaborating on them when in a group situation.

Your Body

___ Entering and exiting a room where you do not know many people.
___ Speaking in front of a group.
___ Maintaining eye contact, keeping your head upright, leaning forward in a personal conversation.

Your Mind

___ Going out with a group of friends when you are the only one without a date.
___ Being especially competent, using your authority and/or power without labeling yourself as aggressive or hateful.
___ Requesting expected service when you haven't received it in a restaurant or store.

Apology

___ Being expected to apologize for something and not apologizing because you believe you are right.
___ Requesting the return of borrowed items or loans of money without being apologetic.

___ Receiving a compliment by saying something assertive to acknowledge that you agree.
___ Accepting a rejection.
___ Not getting the approval of the most significant person in your life.
___ Discussing another person's criticism of you openly with that person.
___ Telling someone that he/she is doing something that is bothering you.

Saying No

___ Saying no -- refusing to do a favor when you really don't feel like it.
___ Turning down a request for a date.

Manipulation

___ Telling a person when you think he is trying to manipulate you.
___ Responding to someone who has made a patronizing remark.

Anger

___ Expressing anger directly and honestly.
___ Arguing with another person.

Humor

___ Telling a joke.
___ Listening to a friend tell a story about something embarrassing but funny you have done.
___ Stating that you think a joke was inappropriate/not funny.

The following questions are ones you should ask yourself when you encounter a situation in which you wish to be assertive:

1. Do I stop myself from acting assertive because of beliefs about how I should or shouldn't act in the situation?

2. Are these beliefs true? Do I have any evidence from my own experience to verify them?

3. Do I stop myself from acting ***assertive*** because I think that the only outcome would be unpleasant, bad, or wrong? On what evidence?

4. Is that rational or are there other alternative outcomes? What are they?

5. Do I stop myself from being assertive for fear I could not handle the results if they should be unpleasant?

6. Is that rational? Or can I think of ways that I could actually deal with the possible difficulty?

Peer Mentoring

By: Ed Turner, Chuck Chumbley, Ed Williams, Chris Barrett, & Michael Barcus

Staff of the RRTC Self-Advocacy Leadership Institutes recognized the need for on-going support for new advocates as they begin to use their newly acquired skills. In order to do this; it was decided to train self-advocates who had some experience to be mentors. A mentor is someone that has accepted his/her disability, and feels okay about themselves and the personal contribution that they make to society. Mentors can make the critical difference to new advocates seeking services and getting good jobs. Such a person is able to provide peer counseling in assisting new advocates to deal with potential employers, as well as issues which may interfere with one's effectiveness on the job. Participants in the Self-Advocacy Leadership Institutes are asked if they would be interested in being trained as mentors.

Interested in Becoming a Mentor
June, 1994 -- November 1998

Individuals Identified as Interested in Mentor Training	70
Mentors Trained	43

Peer Mentorship Training

Peer Mentoring Workshops are focused on introducing skills to improve a self-advocates ability to support and mentor others seeking employment. The development of personal success is crucial in order to obtain adequate and appropriate independent living skills. There are few avenues for acquiring these skills, which is where mentoring can play an integral part. The mentor can wear many hats, including teacher, confidante, and friend. On the following page is a table that identifies the roles and responsibilities discussed with mentors in the Peer Mentoring Workshop.

Mentor Example: Chuck Chumbley

In the fall of 1994, Chuck Chumbley, a person who is quadriplegic, was just becoming reestablished in the community after prolonged stays at residential care facilities. He worked

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Mentor's Roles and Responsibilities

Roles	Responsibility
Advocate:	◆ Support/represent the self-advocate's concerns to human service agencies/employers.
Broker:	◆ Expand the self-advocate's network of contacts. ◆ Facilitate networking with other self-advocates. ◆ Link self-advocate with appropriate services/employment opportunities.
Coach:	◆ Teach self-advocacy skills. ◆ Reinforce effective use of self-advocacy strategies. ◆ Recommend areas in which self-advocate needs improvement. ◆ Clarify and communicate career/employment goals and objectives. ◆ Serve as a role model to demonstrate successful self-advocacy. ◆ Regularly, review the self-advocate's action plans progress.
Counselor:	◆ Identify and understand self-advocate's employment/career-related skills, interests, and values. ◆ Listen to self-advocate's concerns and offer suggestions. ◆ Listen openly for any employment/career ideas and concerns. ◆ Communicate informal and formal realities of navigating service systems. ◆ Recommend training/support opportunities from which the self-advocate could benefit. ◆ Recommend strategies for career direction.
Facilitator:	◆ Establish an environment for open communication. ◆ Schedule regular time to meet with the self-advocate. ◆ Assist the self-advocate to evaluate appropriateness of self-advocacy strategies and career options. ◆ Help the self-advocate plan strategies to achieve goals.
Referral Agent:	◆ Identify resources to help the self-advocate with problems. ◆ Follow-up to ensure the referral resources were useful. ◆ Identify resources for obtaining employment/career progression.

Adapted from: Turner & Perry-Varner, 1996

as a Research Surveyor for Virginia Commonwealth University (VCU) and had recently acquired his own apartment. Being employed, managing his own personal assistant, and beginning to enjoy living life in the community, Chuck had achieved a high degree of independence. He accomplished these goals through the effective use of self-advocacy but was still seeking ways to improve his advocacy skills.

In September, Chuck had the chance and attended the Rehabilitation Research and Training Center (RRTC) on Supported Employment's second Self-Advocacy Leadership Training Institute. During the training Chuck shared a concern about his place of employment. The concern involved working in an office behind locked doors and away from other co-workers. Chuck believed the locked doors not only constituted a fire hazard but was an ADA violation, because he was not able to interact with fellow employees.

Chuck decided to use his newly acquired knowledge about the ADA and self-advocacy skills to resolve the issue. After discussing his concern with his employer, Chuck had a fire marshal assess the situation after which an evacuation plan was developed for employees with disabilities. In addition the employer agreed on a work plan that called for employees with and without disabilities to work together in a more integrated work setting.

Another barrier to confront Chuck was the lack of reliable transportation to go to and from work on time. Again, he utilized his self-advocacy skills to identify the resources he needed to acquire his own lift-equipped vehicle. Chuck enlisted the support of the Virginia Department of Rehabilitative Services to get assistance with the purchase of a lift-equipped vehicle and by late 1995 his dream of having more mobility became a reality.

After participating as a trainer in three subsequent Institutes, Chuck applied to become a mentor in Project Access, a demonstration project at the RRTC. In this project, he had the opportunity to use his skills as a mentor sharing his knowledge and experiences with others. For approximately a year, he mentored the initial six customers with physical disabilities who enrolled in the project and who were residing in residential care facilities. Through his support, these individuals became more comfortable in social settings in the community. Five out of six individuals soon became competitively employed. Chuck's effectiveness as a mentor is due to the enthusiastic way he demonstrates his philosophy of one who has "been there, done that." This causes those he mentors to want to follow in his "wheel tracks."

Mentor Example: Ed Williams

Ed Williams, a person whose primary disability is traumatic brain injury, attended the second of the RRTC's Self-Advocacy Leadership Training Institute. Up until this point, Ed was having great difficulty in obtaining services both for himself and for others. His stated reason for attending the training was to gain knowledge and to his sharpen self-advocacy skills that would enable him to get the vocational services he needed to get a job. He not only wanted this information for himself but wanted to share it with others with brain injury in the Lynchburg area of Virginia.

Although Ed had great interest in all of the Institute's workshops, he was most impressed by the presentation on supported employment. Ed requested to meet with someone who could tell him more about what was happening with supported employment in his area. Even before the Institute ended, the training staff arranged a meeting with Ed and Dr. Wendy Parent, who at that time was directing the RRTC's Job Corps Pilot Project. Wendy immediately recognized Ed's talents and offered him a position with the Project in the Lynchburg area.

Ed's role in the Job Corps Pilot Project was to identify students with disabilities who would be good candidates for that project. Once they were identified, he helped them obtain needed supports, developed compensatory strategies, and assisted them to get necessary accommodations in order to be successful. This assistance was provided through regular students empowerment meetings and one-on-one technical assistance in the various trades and academic classes. In addition he worked with Job Corps staff to increase their knowledge about the unique needs of students with disabilities. Ed's involvement with the project was a contributing factor for its great success.

In 1996, the Virginia General Assembly appropriated funds to the state's Centers for Independent Living (CIL) to establish satellite sites across the state. The Roanoke CIL applied for and received funding for a satellite site in Lynchburg. Ed Williams successfully applied to become the Center's Site Manager and is now fulfilling a dream of providing advocacy services to individuals with disabilities in his area.

Ed's success story is another example of how having the knowledge of one's rights along with having the tools to assert those rights can be very empowering. Sometimes all it takes is having the knowledge, skills, and self-confidence to not only realize your own dreams but to help others realize theirs. This is exactly what Ed Williams is doing for himself and others in Lynchburg.

SUMMARY

Whether these individuals would have been able to accomplish these goals if they had not attended the Institutes, is not clear. What is clear is that they all had an opportunity to gain knowledge and to use self-advocacy skills to make beneficial changes in their lives. Because of their self-confidence, they are proving what can be accomplished through knowledge and self-advocacy.

PERSONAL EXERCISE

Take the mentor challenge. Look over the list on page 62. Beside each role listed in the mentor responsibilities, identify those areas that you are comfortable with and list them below.

Now think of those areas that you are not comfortable with and also list them.

Here are some tips on finding resources to build your skills in the areas you are uncomfortable.

- Call, ask for a brochure of services offered from organizations, agencies, distributors phonebook, library, counselors, organizations, and other individuals.
- Ask to be placed on mailing lists.
- When calling agencies, ask for the name, position title, and extension number of the person you are asking to speak with.
- Ask for references/resources from other consumers when you are obtaining a new item or service (example: van, wheelchair, computer).

- Obtain information from "Consumer Report" magazine on the status of the merchandise you are interested in.

- When obtaining equipment from the Department of Rehabilitative Services obtain three separate names and locations to assist in bidding.

- Obtain written documents from the doctor and occupational/physical therapist, when accessing needed equipment.

- Consider home employment until available work outside the home is reached: tutoring, typing, sales over phone, crafts/hobbies for sale.

- Volunteering may sometimes lead to job placement.

- Obtain information in regards to problems/complaints from Medicaid/ Medicare assistance board when utilizing home health care agency.

- It is very helpful to talk with people who work in the area you are interested in obtaining employment. They can give you an insider's view of their work, what they anticipate the future to be, and how to break into the field.

Personal Assistance Services: A Vital Workplace Support

By: Ed Turner, Michael West, Wendy Strobel, & Michael Barcus

Great disability rights leaders and self advocates like Ed Roberts and Judy Huemann, have proven the value of customer-directed Personal Assistant Services (PAS) through their work in the independent living movement and at the World Institute On Disability (WID). These two pioneers demonstrated the value and cost effectiveness of customer-directed PAS in enabling people with significant disabilities to live in the community. Their work was documented in the research monograph "Attending To America" (Litvak, Huemann, Zukas, 1998). This document has become a blueprint for establishing customer-directed PAS model systems being developed in a number of states. These model systems are enabling countless of thousands of individuals with significant disabilities to live and work in the community.

WHAT ARE PERSONAL ASSISTANT SERVICES?

Personal Assistant Services (PAS) are broadly defined by Nosek (1991) as "assistance from another person with activities of daily living to compensate for a functional limitation" (p. 2). Activities of daily living (ADLs) include such activities as personal hygiene, meal preparation, housekeeping and household chores, and community mobility. In the words of Litvak, Zukas, and Heumann (1987), these are "tasks that individuals would normally do for themselves if they did not have a disability" (p. 1). PAS allows people with severe physical or health impairments to participate more fully in community settings and activities, including employment (West, 1996).

Shortly after the passage of the Americans with Disabilities Act (ADA), the President's Committee on Employment of People with Disabilities (PCEPD) wrote:

> "In the workplace, PAS is provided as a reasonable accommodation to enable an employee to perform the functions of a job. The employer's responsibility for providing reasonable accommodations begins when the employee reaches the job site and concludes when the workday ends. PAS in the workplace does not include skilled medical supervision."

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DUTIES OF PERSONAL ASSISTANTS

The President's Committee on Employment of People with Disabilities Job Accommodation Network (JAN) developed a list of possible tasks that could be done by personal assistants in the workplace. Work-related PAS might include filing, retrieving work materials that are out of reach, or providing travel assistance for an employee with a mobility impairment; helping an employee with a cognitive disability with planning or decision making; reading handwritten mail to an employee with a visual impairment; or ensuring that a sign language interpreter is present during staff meetings to accommodate an employee with a hearing impairment. Each person with a disability has different needs and may require a unique combination of PAS.

Recently, the RRTC conducted a focus group on PAS at the 1998 National Council on Independent Living (NCIL) Conference held in Washington, D.C. This group included employees from CILs who utilized PAS in the workplace or CIL managers who provided such services to their employees as a reasonable accommodation. The input obtained from this focus group lead to the development of the following list of tasks that are required to be done by personal assistants in the workplace.

PERSONAL ASSISTANT'S DUTIES & JOB FUNCTIONS

Personal Assistant Duties	*Job Function Duties*
◆ Assist with grooming tasks	◆ Making telephone calls (if necessary)
◆ Assist with getting beverages	◆ Assist with filing
◆ Assist with food	◆ Taking dictation
◆ Assist with toileting (if necessary)	◆ Voice interpretation (if necessary)
◆ Travel on business trips	◆ Data entry
◆ Assist with dressing and grooming tasks on business trips	◆ Taking notes in meetings
	◆ Reading documents (if necessary)
	◆ Getting and opening mail
	◆ Keeping work-space organized
	◆ Traveling on business trips

WHO USES PAS

Many disability groups can benefit from the PAS in the workplace. For example, people with spinal cord injuries (SCI) can be found in all types of careers utilizing PAS on the job. So having the skill to manage a personal assistant in the workplace is essential. Being able to recruit and hire one's own personal assistant is one way to ensure that the PAS service be reliable and on time. Below are three examples of how people with SCI have made their mark in the community and enjoy satisfying careers with the support of a personal assistant.

Christopher is all too familiar with problems of unreliable services. He relates one horrifying experience when he was left in bed for two days when a personal assistant from a home health care agency never showed. Christopher persevered and now has acquired the resources to hire his own personal assistant that has supported him for the past ten years. He has become a national leader in the campaign for attendant service legislation.

Kira, a businesswoman and a disability rights activist, often cites acquiring reliable PAS as her biggest challenge to becoming re-integrated back into the community. Before accepting a promotion, which necessitated her moving to North Carolina, she consulted with the RRTC in laying the groundwork for a statewide mentoring program for people with SCI. She is currently a high level manager working in the home office of a major corporation.

Susan, a Case Manager, is also well acquainted with the frustrations of finding and keeping a reliable personal assistant. Susan has medical needs, which cause her to juggle services from a home health care agency and her own private provider. This makes for an even more challenging management situation which she does while still maintaining a full-time job. Susan is a regular trainer in the mentoring program and is available if mentors need assistance with specific problems.

The three examples above clearly demonstrate how the ability to manage PAS in the workplace can impact careers. Fortunately, these individuals were able to successfully cope with their PAS situations because they are highly motivated and self-determined individuals. However, when you consider the fast paced track of the rehabilitation process for people with SCI today, there is barely enough time to adjust to the injury much less to deal with PAS management issues. Therefore, people with SCI have been the primary target audience for the RRTC's PAS in the workplace training and technical assistance program.

TRAINING

From its prior experiences, RRTC is convinced an employee with a disability who has the ability to recruit, hire, and manage his or her own personal assistant in their workplace will be more successful in their chosen careers. Having this knowledge and ability can mean the difference between maintaining or losing employment opportunities. It is important for rehabilitation personnel and potential employers to have a better understanding of PAS as a workplace support.

In order for PAS in the workplace to be beneficial, its potential positive impact must be understood. Employees with disabilities must have the skills to find the most appropriate personal assistant who can best support him/her on the job. Personal assistants must be trained on how to provide the necessary support in the most unobtrusive manner. Employers must recognize that an employee with a disability, with the support of a personal assistant, can not only increase productivity but can add diversity to the workforce.

Self-advocacy is a key component of PAS in the workplace. Knowing how to use self-advocacy skills is essential for employees in managing their personal assistant and in relating to employers and immediate supervisors. Employees with disabilities should develop skills needed to recruit, hire, and manage personal assistants to perform the duties in the workplace. Some of the activities will include writing recruitment ads, writing contracts, dispute resolution techniques and learning to use self-advocacy as a management tool.

The personal assistants should understand how to provide essential support to the person that hired him/her in a job setting. Training protocols for personal assistants should stress the differences between providing support in a business environment from a home environment. The training should include methods on ways to remain unobtrusive while providing the level of support needed by the employee.

SUMMARY

In the early 90's, The World Institute on Disability (WID) held a conference of PAS Stakeholders to come up with a plan to develop a national PAS program. One of the outcomes of that conference was to establish a set of values that would drive services provided through a national program. These values are:

1. No medical supervision is required.
2. The services provided include personal maintenance and hygiene including catheterization, mobility, and household assistance.
3. The maximum service limit should not exceed 20 hours per week.
4. Service is available 24 hours a day, seven days a week.
5. The income limit for eligibility is greater than 150% of the poverty level. Further persons who are severely disabled whose income exceeds that established for eligibility should be allowed to buy into an insurance policy, which would provide attendant care. Marital status and consequent financial circumstances should not govern access to personal care assistance.
6. The consumer can utilize individual providers.
7. The consumer hires and fires the assistant.
8. The consumer pays the assistant.
9. The consumer trains the assistant.
10. The consumer participates in deciding on the number of hours and type of service he/she requires.

The Rehabilitation Research and Training Center (RRTC) has long recognized PAS as a valuable support in enabling people with significant disabilities to live in the community. The RRTC shares the belief that PAS services are most effective when directed by people who use them. When people with disabilities are able to control PAS, they can utilize these services when needed without being dependent on a home health care provider.

As customer-directed Personal Assistance Services moves into the employment arena there is little doubt that it will have a positive impact on all concerned. For employees with

significant disabilities it will mean being able to recruit, hire, and supervise a personal assistant that will provide the level of support needed to maximize their efficiency. For personal assistants it will expand employment opportunities in more exciting work environments. For employers and human resource personnel it will provide opportunities to diversify their workforce and increase the productivity of employees with disabilities. Utilizing PAS in the Workplace can be a win-win situation for everyone.

PERSONAL EXERCISE

CHOOSING YOUR PERSONAL ASSISTANT FOR WORKPLACE DUTIES

This chapter discussed many aspects about why using personal assistance services in the workplace is important to an employee with disabilities. Certainly, the process of selecting the most appropriate person to serve as a personal assistant begins with knowing how to recruit and interview candidates for the job. By working through the following exercise, you will become familiar with the steps necessary to recruit and hire a personal assistant in the workplace.

PREPARING TO WRITE YOUR AD:

Using the knowledge you gained from this chapter, write a 50 word or less ad advertising for a personal assistant to assist you in the workplace. State where you plan to run the ad so it will attract the most responses from the most qualified applicants. Answering the questions below before you write your ad may assist you with developing a framework of what needs to be included:

1. What type of business do you work for?

2. Do you work in a "Blue Collar" or "White Collar" environment?

   ___ Blue Collar ___ White Collar

3. Will you need assistance with tasks of a personal nature as well as job-related tasks?

   ___ Yes ___ No

4. How many hours of support do you need on the job a day? No. of Hours_____

5. What type of disability-related challenges do you have on the job?

6. Is there any out-of-town travel associated with your work?

   ___ Yes ___ No

7. How much compensation will you and/or your employer be willing to pay for the personal assistant per week?

   Write Weekly Dollar Amount Here: _____

WRITING YOUR AD:

Sample Ad:

Person with a disability seeks reliable person to serve as a personal assistant at work. The workplace is in a professionally-based academic setting. Most of the duties will be of a clerical nature. However, some assistance may involve helping with grooming, getting food, and beverages. If interested, call #_____ Day or #_____ in the evening.

From the answers to the above questions, develop a very succinct ad with enough information to give applicants a clear picture of the job and what you expect.

(Write your ad here):

MARKETING YOUR AD:

List publications, locations, and web sites where you intend on posting your ad:

1. _____
2. _____
3. _____
4. _____

PREPARING TO INTERVIEW APPLICANTS:

Build ten interview questions around the following qualifying factors:

1. Experience working with people with disabilities.
2. Experience working in your career area.
3. Experience working in human services.
4. Experience working as a personal assistant.
5. Experience working under the supervision of a person with a disability.

List your interview questions here:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

Below are some decisions you need to make before hiring a person.

1. How many applicants will you interview?
2. Where will you interview the applicants?
3. How many references will you ask for?
4. Will you consult with your employer before hiring a person?

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THE CUSTOMER IS RIGHT

A Newsletter for Customers from the Rehabilitation Research & Training Center on Workplace Supports

Winter, 2000

Personal Assistance Services: A Vital Workplace Support in the New Millennium

FEATURED ARTICLES

Worksite Personal Assistance Services: What Consumers Told Us!
Dr. Linda Mona, Research Associate, World Institute on Disability

Role of a Personal Assistant in the Workplace
Ed Turner, Training Associate RRTC on Workplace Supports

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Anthony J. Young

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Susan D. Payne,PAS Coordinator, Virginia Dept. of Rehabilitative Services

Finding a Qualified Personal Assistant
Ed Turner & Chris Barrett

Personal Assistance Service Management
Frank Strong, Jr., Central Iowa Center for Independent Living

Business managers have administrative assistants to answer phone calls, compose letters, file papers, and retrieve work materials. University professors often employ research assistants to do computer searches, make phone calls, compile information, and complete other auxiliary tasks associated with the implementation of a research project. Professional brick layers and master carpenters hire assistants to carry equipment, resupply materials, and clean up a work-site so they can focus on job duties, such as laying bricks or framing in a house. These assistants aid in the overall productivity of a project by enabling the employee to focus on the essential duties of a specific job.

Similarly, Personal Assistance Services (PAS) in the workplace are services provided to an employee with a disability by a personal assistant (PA). Presently, there are many different definitions of PAS. First, most definitions include a person assisting someone with a disability to complete tasks aimed at maintaining well-being, personal appearance, and comfort within the home environment, the workplace, and the community. PAS is a reasonable accommodation that enables an employee to perform the functions of a job. The Job Accommodation Network, better known simply as JAN, developed a list of possible work-related PAS tasks to include:

- Filing or retrieving work materials that are out of reach for someone with a physical disability;
- Driving or travel assistance for an individual with a mobility disability;
- Note-taking and planning support for an employee with a cognitive disability;
- Reading handwritten mail to an employee with a visual disability; or
- Scheduling a sign language interpreter for staff meetings that include an employee with a hearing impairment.

Most employees with disabilities will **not** require PAS as a workplace support. Yet, for those individuals who do need these services, it can mean the difference

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between employment and unemployment. The specific work supports that are provided by a PA are based upon a combination of the employee's required work task needs and personal needs. These combinations create a distinctive composite of work duties for each PA. While the actual job duties of a PA can be extremely varied, there are some duties that would never be included as a responsibility, such as skilled medical care.

Great disability rights leaders and self advocates like Ed Roberts and Judy Heumann have educated the country on the value of PAS and the importance of these services being delivered in a customer-directed fashion. A research investigation, conducted by the VCU-RRTC with independent living (IL) organizations across the country, found that very little has been done to measure the effectiveness of PAS as a workplace support. Additionally, a great deal of confusion exists about the nature of this workplace support among people with disabilities, service providers, rehabilitation professionals, and employers.

The goal of this newsletter is to raise awareness about PAS as a workplace support, share national research findings, provide best practice examples, and distribute resources that will enhance the community participation of individuals with significant disabilities. This issue of the *Customer is Right* was developed with Anthony J. Young, a national expert on PAS, and several national organizations committed to the study and use of PAS as a workplace support. National collaborators for this newsletter include:

- The Rehabilitation Research and Training Center on PAS at the World Institute on Disability,
- VA Department of Rehabilitative Services,
- VCU-MCV Model Systems Project for Spinal Cord Injury, and
- VCU's National Supported Employment Consortium and Rehabilitation Research and Training Center on Workplace Supports.

Worksite Personal Assistance Services: What Consumers Told Us!

by: Linda R. Mona

Are people with disabilities working? Do people with disabilities want to work? According to the 1998 Harris Poll, 7 out of 10 working age people with disabilities say they want to work, but only 29% have jobs. Many researchers and public policy analysts have tried to figure out what prevents people with disabilities from going to work. One reason is the lack of personal assistance services (PAS) within the workplace.

The World Institute on Disability (WID) has conducted research on PAS for the past 15 years within the Rehabilitation Research and Training Center on PAS (RRTC-PAS). In 1994, WID found that only 53 of 144 programs that provide publicly funded PAS allowed or did not prohibit recipients from using program funds to pay for services provided at the workplace. However, in this 1994 survey, worksite PAS was broadly defined and did not distinguish between PAS involving personal care at work (e.g., feeding, bowel/bladder care, etc.) and PAS with work-related tasks (e.g., filing, phone use, reading mail, etc.). Our research staff became more intrigued with worksite PAS and decided to look at this topic more closely.

Worksite PAS Defined

The RRTC-PAS defines PAS as "a person assisting someone with a disability to perform tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interaction with the community and society as a whole." This general definition encompasses both types of PAS that may be needed on the job—personal care and assistance with job specific tasks. The primary goal of our initial worksite PAS research was to learn how people with disabilities identify, arrange, and use PAS at work. To help us identify relevant areas to pursue, we conducted a series of focus groups with consumers utilizing PAS.

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Current Study

Included in our focus groups were individuals with a wide range of disabilities who were currently using and/or had previously used PAS . The final focus groups included individuals with the following disability types: mobility, vision, cognitive, and psychiatric disabilities. Our final sample included 17 individuals (14 men and 3 women) with a wide range of occupations (e.g., consultant, managerial, technical, disability industry, academic, administrative, self-employed).

Three focus groups were conducted in California and Georgia. All group locations were accessible to persons with varying disabilities (e.g., wheelchair accessible location, sign language interpreter upon request, written materials available in Braille, PAS provided on site). Participants spoke about a variety of interesting themes including:

- Experience explicit and/or perceived discrimination.
- Issues with self-identification of disability and worksite PAS needs.
- Experience fewer difficulties finding assistance with work tasks versus personal care tasks.
- Knowing when and how to disclose PAS workplace needs.
- Knowing who and when to ask for worksite PAS.
- Learning how to negotiate relationships with home and work providers.
- Experience better worksite PAS arrangements when services are contracted.
- Discussing worksite PAS needs with a supervisor for positive and negative points.
- Using PAS to shape job selection.
- Many industrial jobs are comfortable with accepting disability.
- Customer-directed service brings greater satisfaction.

Overall, the consumers indicated more satisfaction with using PAS within their work environments when they felt comfortable disclosing their disability status with employers, perceived little or no employer discrimination, and received support about workplace PAS from their supervisor. In addition, important steps in establishing satisfactory worksite PAS arrangements included negotiating clear boundaries within consumer/provider relationships (e.g., paid positions for PAS providers and clarity about work schedules) and being able to choose their own provider (i.e., consumer direction).

Consumer's Suggestions

Participants offered numerous suggestions for improving PAS in the workplace. These recommendations included:

- Fight for federal and/or state money for worksite PAS.
- Learn how to articulate PAS needs to an employer.
- Find money to pay your own PAS providers whenever possible.
- Fight for higher salaries for PAS providers.
- Increase disability awareness of employers.
- Involve employers in disability-related policy development.
- Increase education for human resources departments.

Future Research Directions

Based on the information gathered from the focus groups, we are now in the process of creating a detailed questionnaire to be distributed to consumers in January, 2000. Through this process, we hope to gain a more comprehensive understanding of PAS in the workplace so that we can be influential in developing and supporting PAS policy. We will disseminate our findings to help consumers become more informed about worksite PAS and spread the word to employers, with whom we must develop strong collaborative relationships.

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Rehabilitation Research & Training Center on Personal Assistance Services (RRTC-PAS)

The Rehabilitation Research and Training Center on Personal Assistance Services seeks to further understanding of how personal assistance services (PAS) systems can improve the economic self-sufficiency, independent living, and full integration of people with disabilities into society. It is accomplishing this goal through studying PAS models for independent living. The major focus of the RRTC-PAS is to promote consumer directed services and choice.

For more information regarding the RRTC on PAS, contact:

World Institute on Disability
510-16th Street
Suite #100
Oakland, CA 94612-1500

Visit our Web Site at:

www.wid.org/pas/index.html

or E-mail to:

mailpas@wid.org

Role of a Personal Assistant in the Workplace

by: Ed Turner

What is the role of a personal assistant in the workplace? To answer this question, the VCU-RRTC conducted two focus groups comprised of individuals who use personal assistant services on a daily basis. The focus first group involved participants with little or no experience directing their own personal assistant. The second focus group coincided with the national conference of the National Council on Independent Living (NCIL) with participants comprised of experienced customer-directed PAS users, and CIL employees who use and provide PAS as a reasonable accommodation.

The development of a definition of what is meant by PAS when applied to a workplace setting was the major outcome of this focus group research. Group members agreed that the definition needed to be a single, simple and clear statement that was meaningful to employees with disabilities, personal assistants, and employers. The definition they developed is:

"Personal assistance services in the workplace are services provided to an employee with a disability by a personal assistant to enable the employee to perform the essential duties of a job more efficiently."

Both focus groups were able to quickly generate a detailed list of workplace tasks that can be performed by a personal assistant at a job site. The table below organizes these lists into four major job functions. For each job function there is a description of several possible workplace tasks that may be directly associated with the particular job. It is important to note that this table represents a full range of possible workplace support options that can be provided by a personal assistant.

General Job Duties that can be Performed by a Personal Assistant in the Workplace

Job Functions	Description of Possible Tasks
Activities of Daily Living Aid	Provide assistance with combing hair, applying make-up, straightening clothes, eating lunch, and/or other activities of daily living throughout the work day and on business trips.
Business Travel Companion	Provide assistance with making travel arrangements, completing travel reimbursement paperwork, serve as personal driver, facilitate the acquisition of chauffeuring services, and/or serve as a traveling companion on business trips.
Office Services Specialist	Provide assistance with getting mail, opening mail, making telephone calls, keeping work-space organized, making copies, filing, taking dictation, and entering data.
Meeting Assistant	Provide interpreter services or facilitate the acquisition of an interpreter, voice interpretation, meeting note taker, and/or document reader.

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Defining the role and the function of PAS in the workplace will ultimately prove important to increasing access to the employment for individuals with significant disabilities. Ensuring that the employees using PAS directly manage their own supports is vital to the process. Managing PAS would include participating in such activities as recruiting, hiring, and evaluating the personal assistant. Yet, before large numbers of employees can begin accessing this support, additional research and regulatory policy clarification must be given to determine:

- supports considered to be a reasonable accommodation and therefore paid for by the employer; and
- supports considered to be personal in nature and funded by medicare or other funding sources.

Once these important issues are addressed, employees with significant disabilities will be able to expand their work opportunities in exciting and challenging work environments, and employers will be in a position to benefit from enhanced diversity within their business settings.

Examples of Personal Assistance Services in the Workplace

by: Anthony J. Young

While using PAS as a reasonable accommodation is new to many businesses, many employers are doing a good job at providing this work support as a reasonable accommodation. The following are a few examples of how employers have provided PAS for employees with disabilities. While the situations below represent a small sample of the actual services possible within the workplace, they demonstrate how a PA can be used in combination with other work supports.

Adjustments to Bob's Work Schedule

Bob is a technology and telecommunication policy specialist with cerebral palsy which affects his mobility and speech. Bob uses a personal assistant at his home to assist him with bathing, eating, shopping, dressing, transferring, and toileting. Over the years, Bob has been confronted with work scheduling difficulties due to transportation issues associated with arranging for home assistants to arrive very early in the morning. These two problems made it difficult for Bob to consistently arrive to work on time. Bob's employer made an adjustment in his work schedule that allows him to work a flex day beginning one hour after the office regularly opened and ending one hour after the office closed. Security personnel were informed of the changes to Bob's schedule and were made available to unlock security doors for him when he finished work. In addition, the employer hired a part-time PA to provide supports to Bob related to eating and use of the bathroom during work hours.

Co-worker Assigned to Martha

Martha, an employee with quadriplegia, uses a power wheelchair for mobility and the services of a PA for help with bathing, eating, shopping, dressing, transferring, and toileting. Martha is employed as a program manager. As part of her job, she must develop office procedures and operation manuals, answer questions on how to implement procedures and operations, collect data, and write reports. To perform the majority of these job functions, Martha is highly dependent on her personal computer. To increase Martha's productivity, her employer purchased a voice dictation program that enables her to verbally operate her personal computer for research, e-mail, report writing, and data collection. A co-worker was assigned to assist Martha with the initiation and removal of the voice dictation headset microphone, and another co-worker was trained to assist with eating, drinking, and toileting.

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Jack's Work Station Modification

Jack, an employee who is legally blind, must prepare memos, briefs, reports, technical assistance papers, and performance reports. These items are developed using a variety of resources, including books, newspapers, verbal reports, and Internet materials. Jack's employer purchased a print reader and a closed circuit TV system to assist him in accessing these products. In addition, a voice output screen reading software was provided to access resources found on the Internet. A co-worker from a shared labor pool was assigned to provide PA supports, such as reading printed material that could not be accessed. Jack trained his PA to read in a manner best suited to his work.

An Office Services Specialist for Gail

Gail, a training specialist with cerebral palsy, uses an electric wheelchair and is employed as a training associate with a large state bureaucracy. As a training associate, Gail is responsible for designing, developing, and delivering personnel training events. Additionally, she must write articles and develop training materials and products. Gail was in need of a PA to take voice dictation, make copies, read documents, develop meeting minutes, open mail, answer the phone, and file. The state system that employed Gail did not have "personal assistant" as an existing job title. Gail and her employer developed a job description for a part-time office services specialist and hired the assistant to serve as her PA. Gail directly supervises and evaluates the work of the new office services specialist serving as her PA.

Adjustments in an employee's work schedule, modifications in an employee's workstation, assignment of a co-worker for assistance, and the direct hire of PA are just a few of the many creative ways that employees can be supported with PAS in the Workplace. Critical to this process is the need for employers and employees to openly discuss work situations and/or concerns and to work together to develop possible solutions for job success. When this is done in an open manner, creative reasonable accommodations can usually be negotiated.

Acquiring PAS in the Workplace

by: Susan D. Payne

It comes as no surprise to many individuals with significant disabilities that getting or keeping a job can present a number of problems. One major challenge is finding appropriate and reliable personal assistance services (PAS). For many individuals with disabilities, the assistance of another person is necessary to accomplish normal activities of daily living at home and in the workplace. For these individuals, maintaining employment is often dependent on finding and keeping one or more personal assistants who are interested in providing consistent care, both in the home and at work.

In Virginia, several options exist for individuals who require PAS if they are to work successfully. Sometimes called attendant services or personal care, PAS are eligibility based with criteria that consider the disability, the subsequent functional limitations, and the financial resources of the consumer. Using the consumer-directed model where the consumer is the employer, the Virginia Department of Rehabilitative Services (DRS) manages three PAS programs. Each of these programs requires that consumers participate in a comprehensive assessment of need and a consumer-orientation training program provided through the Centers for Independent Living. A formal application is required, and the consumer may be responsible for a portion of the cost of services.

The Department of Rehabilitative Services manages the three options described on the following page for acquiring Personal Assistance Services. Other possible sources for PAS include Companion Services through the Department of Social Services and services through the Veterans Administration. PAS can also be personally arranged by the consumer through friends, family members, or other community supports. Because of the multiple potential sources of PAS and the various eligibility criteria for each, consumers should seek information and assistance from their own state Department of Rehabilitative Services or local Centers for Independent Living.

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Option #1: Vocational Rehabilitation PAS

For some consumers with disabilities who are pursuing employment by applying for or currently receiving vocational rehabilitation (VR) services through DRS, VR PAS may be an option. To access PAS through the VR PAS program, the consumer should ask his or her VR counselor to submit a PAS application to the PAS Coordinator at the DRS Central Office. PAS must be required for the individual to participate in an Employment Plan, developed by the consumer and counselor that outlines plans for achieving an employment outcome. The PAS Coordinator can provide technical assistance to the consumer, representative, or counselor who is seeking information about PAS.

Option #2: State-Funded PAS

State-funded PAS may be an option for individuals with severe disabilities who require the assistance of another individual to perform the physical tasks of daily living. Examples of such tasks would include, but are not limited to, positioning, dressing, and grooming. A fund of last resort, this program serves individuals who cannot access PAS through any other source and have the ability to independently manage their own PAS. Funding is limited, and there is a waiting list for services.

Option #3: PAS for Individuals with Brain Injury

PAS for individuals with brain injury is a relatively new initiative. While this program is consumer-directed, the consumer must have a representative who will assist in managing the PAS. In addition, the personal attendant services must be obtained from the Virginia Department of Medical Assistance Services (DMAS) through Medicaid-funded Waiver programs. These programs include the Technology Assisted Waiver, Consumer-Directed Personal Attendant Services Waiver, Elderly and Disabled Waiver, and Mental Retardation Waiver. Consumers seeking assistance through these programs must participate in a nursing home pre-screening provided by the Departments of Health and Social Services and must meet specific eligibility criteria based on functional limitations resulting from a disability and financial need. Information about these programs can be found though the local Departments of Health and Social Services or Centers for Independent Living.

ASK THE ADVOCATE

Q: Is a medical assessment a requirement to determine eligibility for most consumer-directed PAS Programs?

A: NO -- Even though the Uniform Assessment Instrument is used to determine eligibility for most consumer-directed PAS programs, it is not administered by medical personnel. For example, in both of Virginia's consumer-directed PAS programs, the assessment is done by staff from Centers for Independent Living (CIL) through a contract with the Department of Rehabilitative Services (DRS) and the Department of Medical Assistance Services (DMAS).

As PAS moves into workplace settings, these assessments will need to focus on employment support provided by personal assistants. Employment specialists, vocational service providers, and/or CIL staff will need to become skilled at working with the employee to analyze his/her need for on-the-job assistance and accommodation. This assistance will enable the employee with a disability to more efficiently accomplish work-related tasks. The increased efficiency will demonstrate to employers the cost-effectiveness of providing PAS as a reasonable accommodation at the workplace.

For further information regarding the listed options for personal assistance services in Virginia contact:

Susan David Payne, Manager
Personal Assistance and Nursing Home Outreach Services
Department of Rehabilitative Services
1-800-552-5019
or
contact your Local Center for Independent Living

Finding a Qualified Personal Assistant

by: Ed Turner & Chris Barrett

The process of finding a qualified Personal Assistant (PA) for workplace duties requires a great deal of preparation and work for the new employee with a disability. Critical to this process is the development of a well written, detailed job description of personal assistant duties prior to the recruitment process. The first step is a self-assessment to determine discrete workplace needs that could be completed by a personal assistant. Some employees benefit from the assistance of an employment specialist or other rehabilitation professionals to facilitate the self-assessment. The results are then categorized into job functions that are used in writing the detailed job description for hiring the personal assistant.

Once an accurate and complete job description has been developed, recruitment tactics must be initiated. Recruitment is the most difficult part of the entire process. Where do you look for a personal assistant? How will you find the right person who not only matches with the workplace needs but will also match-up with the corporate culture of the workplace? The answer to these questions can be found by taking a common sense approach. The first step is to begin with a solid network of family and friends. Individuals closest to the employee possess the greatest knowledge to begin the PA match-up process. The next step is to develop a list of potential places to target recruitment efforts. After identifying those locations, the employee must be willing to devote long hours to obtain the best match. The list below gives 12 strategies for recruiting a personal assistant.

Most people will agree that PAS in the workplace is not a common work accommodation. Yet, if greater numbers of people with disabilities are going to access employment, increased emphasis on the use of PAS is needed. People with disabilities, employers, and rehabilitation professionals must understand the potential benefits of a PAS. Employees with disabilities need to develop the skills necessary to hire and manage the PA services needed. Finally, education and training must be extended to individuals interested in becoming personal assistants to assist them in acquiring and developing the competencies needed to provide necessary work supports in an unobtrusive and competent manner. Once this education occurs, employers will begin to recognize the advantages of utilizing PAS as a workplace support accommodation that increases worker productivity while adding diversity to the workforce environment.

Twelve Strategies for Recruiting a Personal Assistant

1. Advertise in several local newspapers and speciality papers.
2. Call the local Center for Independent Living and request their personal assistants registry.
3. Use your friends and family network.
4. Tell your co-workers that you are seeking a personal assistant.
5. Post a job ad on bulletin boards at local churches.
6. Contact local civic clubs to request their assistance with recruitment effort ideas.
7. Advertise in publications developed at local high schools, community colleges, and universities.
8. Investigate employment opportunity advertisements in local newspapers.
9. Scan the Yellow pages of your local telephone directory for home care service providers.
10. Contact local technical schools that are training students for health care professions.
11. Advertise for a PA within the company.
12. Advertise in business newsletters and other business publications.

Values Driving PAS

In the early 90's, the World Institute on Disability (WID) held a conference of PAS Stakeholders to come up with a plan to develop a national PAS program. Conference participants established a set of values that would drive PAS provided through a national program.

THESE VALUES ARE:

1. No medical supervision is required.
2. The services provided include personal maintenance and hygiene such as catheterization, mobility, and household assistance.
3. The maximum service limit should exceed 20 hours per week.
4. Service is available 24 hours a day, seven days a week.
5. The income limit for eligibility is greater than 150% of the poverty level. Individuals who are severely disabled and whose income exceeds that established for eligibility should be allowed to buy into an insurance policy that provides attendant care. Marital status and subsequent financial circumstances should not govern access to personal care assistance.
6. Individual providers can be utilized by the consumer.
7. The consumer hires and fires the assistant.
8. The consumer pays the assistant.
9. The consumer trains the assistant.
10. The consumer participates in deciding on the number of hours and type of service he/she requires.

Personal Assistance Service Management

by: Frank Strong, Jr.

Often, one of the most critical factors of assuring the success of a person with a disability is personal assistance services (PAS). This service can help a person with a disability successfully accomplish the "essential functions of the job." These essential functions, described in the American with Disabilities Act, are the work activities that must be accomplished in order to carry out assigned work duties. Many of these work assignments can be accomplished by people with significant disabilities with the support of a personal assistant.

In the past, there were job descriptions that required having a driver's license, lifting , and specific vision activities which typically disqualified many individuals with disabilities. Now, with the aid of a personal assistant, an applicant with a disability can perform many of these tasks, even if the applicant is not able to drive or lift heavy objects as long as these activities are not "essential functions" of the job. For example, a counselor or sales person who needs to travel to provide services or sell products can still travel without a driver's license if the worker with a disability can obtain personal assistance services.

Until recently, there were few resources to assist in recruiting, supervising, and training of a personal assistant. Now, programs such as ours at the Central Iowa Center for Independent Living (CICIL) have developed user-friendly training programs designed to assist people with disabilities find and keep personal assistant service providers. The format of the training is interactive and designed for consumers and providers. A video tape version of the consumers training curriculum is in production. Upon completion, people with all kinds of disabilities will be able to access this information. All training materials will be available in alternative formats.

The CICIL wanted to find out how other organizations defined personal assistance services, so CICIL conducted a national survey and mailed 360 questionnaires to Independent Living Centers across the United States, as well as Canada, Puerto Rico and the Virgin Island. A 39% response rate was achieved with 139 completed surveys returned to the CICIL. A sample of the survey results can be found on the following page.

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National Survey Conducted by CICIL -- sample responses

Does your CIL offer/provide Personal Assistance Services? **Yes -- 98 (70.5%)** **No -- 41 (29.5%)**

Comment: Most of the CILs serve at a minimum, as a referral agency. Some provide the service but to a limited number of consumers, such as only to their employees, only while consumers are at the center, or only for conferences. (Most CILs who answered No to this question did not indicate any response to the rest of the questions on the survey.)

Does your CIL place ads in local papers to recruit personal assistance providers? **Yes-- 61 (55.5%)** **No -- 49 (44.5%)** **N. A. -- 29**

Comment: Most centers use traditional ads and public service announcements. Some supplement or replace these with alternative forms of advertising, i.e., fliers, college newspapers, recruitment at public speaking engagements, etc. Some centers consider it the consumers' responsibility. Several centers sited the ineffectiveness of placing such ads.

Do you meet personal assistance applicants in person? **Yes -- 71 (64.5%)** **No -- 39 (35.5%)** **N. A. -- 29**

Comment: Most centers meet the applicant first. Some consider interviewing the consumer's responsibility. Centers sometimes handle the paperwork involved.

Does your CIL offer training to people interested in becoming personal assistance providers? **Yes -- 43 (36.8%)** **No -- 74 (63.2%)** **N.A. -- 22**

Comment: Some CILs refer PSAs to other agencies for training. In consumer-directed programs the training is left up to the consumer. Some centers not providing this training either can't afford the service or have had no requests for this type of program. Those CILs who do offer PAS training vary widely in training content from disability awareness and IL philosophy to first aid and transfer techniques. Training frequency varies from center to center ranging from three or four hour sessions to a 13 week training program. Centers provide literature, manuals, software and/or videos to train PSAs.

For more information about the programs developed or the survey sent by the Central Iowa Center for Independent Living contact:

Central Iowa Center for Independent Living (CICIL)
1024 Walnut Street
Des Moines, Iowa 50309-3424

(515) 243-1742 VOICE
(515) 243-2177 TTY
1-888-503-2287
<strongman@raccoon.com>

ANNOUNCING Two New Products from the RRTC on Workplace Supports

NEW

The Impact of Supported Employment for People with Significant Disabilities: Preliminary Findings from the National Supported Employment Consortium

Edited by: Grant Revell, Katherine J. Inge, David Mank, & Paul Wehman

This is the first monograph published by the National Supported Employment Consortium. It provides information on presenting a wide variety of evaluation studies that are works in progress. The monograph's range of authors and topics reflects the comprehensive nature of the SEC evaluation effort. There are fifteen papers that frame the results in a practical, best practice oriented viewpoint.

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Articles in this monograph include:

- Supported Employment: Critical Issues and New Directions -- *by: Paul Wehman & John Bricout*
- Paying for Success: Results-Based Approaches to Funding Supported Employment -- *by: Jeanne Novak, David Mank, Grant Revell, & Dan O'Brien*
- Supported Employment: It's Working in Alabama -- *by: Valerie Brooke, Howard Green, Dan O'Brien, Byron White, & Amy Armstrong*
- Empirical Evidence of Systems Change in Supported Employment -- *by: Martha McGaughey & David Mank*
- The Quality of Supported Employment Implementation Scale -- *by: Gary R. Bond, Jeff Picone, Beth Mauer, Steve Fishbein, & Randy Stout*
- A Profile of Vocational Rehabilitation Interagency Activity Improving Supported Employment for People with Disabilities -- *by: Susan M. Foley, John Butterworth, & Amy Heller*
- Interagency Agreements Encouraging Supported Employment for People with Disabilities: Preliminary Report on Exemplary Practices -- *by: Susan M. Foley & Joseph Green*
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